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Visualizing the Other: A Phenomenological Analysis of the Objectification of the Body in Biomedical Research Using Human Subjects

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Visualizing the Other: A Phenomenological Analysis of the Objectification of the Body in Biomedical Research Using Human Subjects

by

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Dedication

To my beautiful wife, Dara. I am eternally grateful for all of your support, patience, and acts of kindness, both large and small, over the years.

To my wonderful daughter, Sophia. I hope that you will always live in a world full of love and respect.

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Throughout the brief history of biomedical research using healthy subjects, human subjects have been treated by some clinician-investigators as mere objects of study. This scientific objectification has led to some egregious violations of human dignity. This historical pattern of dehumanizing treatment indicates that some investigators saw subjects as mere objects, undeserving of respect or recognition of their intrinsic value. In response, normative guidelines and methodological constraints have been imposed upon the scientific community to prevent future abuses. Foremost among them is the imperative that investigators show respect for research subjects as persons. However, investigators have not been trained to think of subjects as persons. Instead, the rhetoric of reductionism within medical science has perpetuated the view that persons are bodies and bodies are merely biological objects. This dissertation aims to reshape the foundation of research ethics in order to focus on embodiment and, in particular, how clinician-investigators visualize and conceptualize human research subjects' bodies. This dissertation aims to broaden and deepen the moral vision of clinician-investigators by introducing ways of seeing the body that help uncover the intrinsic value of the human research subject. By developing an ethic of recognition, reciprocity, and respect that is grounded in an aesthetic appreciation of the subjectivity of human research subjects, medical humanists will be able to teach investigators how to cultivate a more capacious sense of respect for persons.

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List of Abbreviations

ACHRE	Advisory Committee on Human Radiation Experiments
AEC	Atomic Energy Commission
CMR	Committee on Medical Research
DOD	Department of Defense
DOE	Department of Energy
NIH	National Institutes of Health
RCR	Responsible Conduct of Research
TCDD	2,3,7,8—tetrachlorop-dibenzodioxin
UTMB	University of Texas Medical Branch

Introduction

Throughout the brief history of biomedical research using healthy subjects, human subjects have been treated by some clinician-investigators as mere objects of study. This scientific objectification has led to some egregious violations of human dignity. In response, normative guidelines and methodological constraints have been imposed upon the scientific community to prevent future abuses. Foremost among them is the imperative that investigators show respect for research subjects as persons. However, investigators have not been trained to think of subjects as persons. Instead, the rhetoric of reductionism within medical science has perpetuated the view that persons are bodies and bodies are merely scientific objects. In this context *reductionism* is taken to mean a general discursive strategy for simplifying the complexities of embodiment and subjective experience that results in the scientific objectification of human research subjects' bodies. This rhetoric of reductionism is morally pernicious because it narrows clinical investigators' moral vision. I define *moral vision* as a description of the way investigators "see" subjects' bodies, which informs how they treat research subjects. Moral vision develops primarily within the context of training in the methodology of medical research. Through their exposure to reductionistic language as part of their training as medical researchers, clinical investigators are persuaded that the healthy subjects sitting in front of them in the clinical research center are not persons, but are merely scientific objects. This way of seeing has important moral implications because some investigators have acted according to their visual and conceptual senses of subjects' bodies. In other words, for them seeing subjects' bodies through the lens of these

metaphors justifies treating those bodies as one would machines, factories, or crops in the field. In this sense, their moral vision has been corrupted by a variety of rhetorical devices that have undermined their ability to adequately show respect for persons.

If medical humanists and clinical investigators are to take the notion of respecting persons seriously as an ethical response to the scientific objectification of the body, a way must be found to recognize human subjects as persons, not merely as bodies, objects, or means to another's ends. In this dissertation I explore these means within the conceptual framework of the medical humanities, with a special focus on phenomenology as a way of uncovering the subjective experience of embodiment. As such, this work is primarily addressed to bioethicists, medical humanists, and clinician-investigators. By *clinician-investigators* I am not simply referring to those medical professionals who design research protocols and oversee their implementation through sporadic visits to the research site. Instead of this rather narrow understanding of the term, I mean to offer an approach that addresses any person who has face-to-face contact with research subjects. In the current decentralized and compartmentalized research climate, it would be impractical to speak only to clinician-investigators. What was once a face-to-face relationship between subjects and investigators has been enlarged to include nursing staff, physical therapists, patient-care technicians and others who are part of the research team. Thus, when I refer to clinician-investigators or simply investigators, I have the research team in mind as interlocutors in the ethical conversation I propose in this dissertation. This widening of the intended audience is meant to address a fundamental flaw in the current focus on rules and regulations in research ethics.

The problem with the current focus is that it places the source of moral responsibility with normative guidelines that do not address how investigators should respect persons. Instead of instructing investigators on how to recognize the intrinsic value of persons, which is expressed through their subjectivity, embodiment, and their relationships with others, the current norms focus on autonomy and decision making within the research context. These expressions of personhood must be recognized by investigators if they are to be able to truly respect research subjects as persons. Instruction in how to develop the sensitivity necessary to respect research subjects as persons through the cultivation of their moral vision should be part of the ethical training of investigators. In this sense, research ethics needs to be supported by a moral aesthetic. I define a *moral aesthetic* as a general theoretical framework for using the tools of aesthetic perception and judgment to inform moral deliberation and refine moral intuition. If moral vision provides guidance for how investigators should treat research subjects, it must be trained to focus on the face of the *Other* as the root of moral obligation. It is the ethics of this face-to-face encounter that I argue should be the focus of research ethics. Training clinical investigators to expand their moral vision by developing an aesthetic appreciation for subjects is an important and feasible educational goal. By training clinical investigators to see subjects as persons and not merely as scientific objects, medical humanists and bioethicists can work to repair the moral failures of the past and prevent the next great moral crisis in research ethics from occurring.

This dissertation aims to reshape the foundation of research ethics in order to focus on embodiment and, in particular, how clinician-investigators visualize and

conceptualize research subjects' bodies. In the past, some clinician-investigators have treated subjects' bodies as mere objects. This historical pattern of dehumanizing treatment indicates that they saw subjects as mere objects, undeserving of respect or recognition of their intrinsic value. If subjects live through their bodies, then how investigators treat these bodies is indicative of how they view persons. Some investigators have been persuaded by a pervasive rhetoric of reductionism to narrow the scope of their moral vision and subsequently have failed to show respect for persons. This dissertation aims to broaden and deepen this moral vision by introducing ways of seeing the body that help uncover the intrinsic value of the Other. By developing an ethic of recognition, reciprocity, and respect that is grounded in an aesthetic appreciation of the subjectivity of the Other, medical humanists will be able to teach investigators how to cultivate a more capacious sense of respect for persons.

In the first section of this introduction, I will outline the rhetoric of reductionism and the discursive practices that support it. In the second section, I will briefly describe the concept of the body-subject in order to indicate what the traditional analysis of the normative structure of research ethics overlooks. In the final section, I will outline the embodied view of respect for persons that I argue should be added to the account already given in the Belmont Report.

When the term *rhetoric* is used in everyday conversation, it is generally meant to denigrate the view being espoused as either false speech or as intended to provoke an emotional reaction that serves only the needs of the rhetor. Politicians are known for using the term to describe the positions of opposing parties as a way of highlighting their impracticality or ideological inconsistency. Ernesto Grassi refers to this kind of speech,

"which only refers to images because they affect the passions" but does not arise from insight, as "false speech."[1] I will not discuss this understanding of rhetoric within this dissertation, as it neither leads to insights into the nature of scientific objectification nor presents any means for disclosing a more capacious sense of respect for persons. Instead, I will focus on the kind of "true" rhetoric that reveals the foundational images or *archai* on which language is founded.[2]

As understood by the ancients and some Renaissance scholars, true rhetoric uses imagination and intuition to discover these foundational images. These images disclose the topics that rhetors may appeal to in order to persuade others. Meaning is then constructed as a dialogical project of recognizing relationships and similarities among concepts, images, schemas, values, beliefs, and emotions. Through the use of metaphor, interlocutors are able to find similarities among disparate concepts by using a central image to link these concepts. In Grassi's view, the central value of metaphorical thinking is to serve as a basis for transferring sense experience to language. In this dissertation, I will use the term *metaphor* to describe the process by which various images of the body are disclosed to investigators through language. To discern how these metaphors are inscribed in the discourse of human subjects research and how these rhetorical devices have persuaded some investigators to act in morally problematic ways is the task of the second chapter of this dissertation. To lay the groundwork for this and other chapters, more must be said about the nature of scientific discourse.

Scientific discourse is both demonstrative and metaphorical. In its more mathematical and logical forms, it seeks to describe objects and their behavior

[1] Ernesto Grassi, *Rhetoric as Philosophy: The Humanist Tradition*, trans. J. M. Krois and Azizeh Azodi (University Park, PA: Pennsylvania State University, 1980), 32.

[2] Ibid.

nomothetically and apodictically. In its quest for precise descriptions of phenomena, it must "restrict itself to finding what already is contained in the premises but not yet explicit or obvious."[3] Yet, the basis for this nomothetico-deductive speech is in the metaphorical speech that illuminates these first premises. In Grassi's view, *ingenium* is the capacity for "catching sight of relationships, of *similitudines* among things."[4] Scientific discourse is a work of *ingenium* or imagination as much as it is a product of observation and deduction. Part of the task of a rhetorical analysis is to discover the *archai* in the rhetoric of reductionism as well as in the subjective experience of embodiment. Discerning the foundational images at the root of these discourses is essential for determining how investigators envision the human body. Furthermore, by paying particular attention to how the use of metaphors within these discourses shapes the clinical gaze, various pedagogical strategies for improving the investigator-subject relationship may be discovered. Before considering how these metaphors operate, I will sketch a brief definition of the rhetoric of reductionism.

A *rhetoric of reductionism* may be defined as the use of foundational images of embodiment within the research enterprise that persuades investigators and subjects that human bodies are mere objects of scientific inquiry. This form of reductionism oversimplifies the complexity of the lived experience of embodiment. In this way, the rhetoric of reductionism shares some features with the more well-known iteration of this concept, which originates in the philosophy of science. However, in this dissertation I am using the term *reductionism* to focus attention on the discursive strategies that dehumanize and objectify body-subjects. This rhetoric is embedded within the discursive

[3] Ibid., 97.
[4] Ibid., 8.

and instrumental frameworks of the research enterprise itself and expressed through the process of inscription, which I will describe in detail below. Indeed, it is the context of medical research that tacitly bestows the weight of a moral imperative upon this reductive model of embodiment, transforming it from an epistemically helpful means for studying the body to a morally pernicious objectification of the body. This form of reductionism is itself based on an image of the investigator as an unbiased and ahistorical observer whose own subjectivity poses a threat to his scientific judgment. When speaking of any kind of rhetoric, one must identify the foundational image upon which it rests. The foundational image of medical research is the book of nature, which investigators read and discern through empirical observation.[5] This image informs the premise that investigations of the human body reveal the complete truth of the body, cleansed of subjective images, beliefs, and values. This kind of image is necessary if medical science is to have predictive ability, yet it fails to admit the view that the body often retreats from our attempt to understand it objectively. Objective knowledge of other bodies is possible, but it is not the starting point of our encounter with them.

To be clear, the metaphors described in the following pages have shaped the scientific minds of clinician-investigators both morally and epistemically. For the purposes of this dissertation, I use the term *epistemic* to describe the empirical methods for producing objective knowledge through observation and experimentation as well as the institutional structures that organize scientific knowledge. These metaphors guide moral action by persuading investigators that a particular way of seeing and treating the

[5] The origins of this image in modern science are derived from the medieval period. See Allen G. Debus, *Man and Nature in the Renaissance* (Cambridge, UK: Cambridge University Press, 1978) and Michel Foucault, *The Order of Things: An Archaeology of the Human Sciences* (New York, NY: Random House, 1970).

body of the Other is valid both epistemically and morally. They both stipulate claims about the moral and epistemic worth of the body and illuminate the practice of these investigators. They can persuade investigators to seek knowledge in a certain way and in so doing persuade them to treat other human beings in a way that coincides with their search. One of the more well known of these metaphors emerged out of mechanistic philosophy, which was embedded in the history of medicine. The metaphor of the body as machine (mechanical metaphor) is a concept that is well-known to scholars of René Descartes as well as those modern bioethicists who trace the root of the biomechanical model of disease back to his meditations and discourses. Another foundational image and metaphor share this Cartesian foundation. However, this line of rhetorical thought emerged out of a historical and philosophical reconstruction of how epistemic and moral values external to medical research embedded themselves within the discourse of embodiment. The metaphor of the body as factory (industrial metaphor) is the product of the industrialization of world economies, the development of biostatistics as a field of inquiry, the bacteriological revolution, and the professionalization of medicine. It expresses the foundational image of the body as productive on an industrial scale. A third metaphor under investigation was coined by dermatologist Albert Kligman as a way to describe how he saw his subjects. To him, their bodies were mere agricultural commodities (agricultural metaphor), waiting to be harvested. When put to use these metaphors guide moral action by persuading investigators that a particular way of seeing and treating the body of the Other is valid both epistemically and morally. They both stipulate claims about the moral and epistemic worth of the body and illuminate the practice of those investigators who have been persuaded by them. The alternative

metaphors I offer are likewise embedded in the social fabric, albeit not in scientific discourse. While they vary in their epistemic value, they all possess a strong moral content. Each is derived from claims about the body that have been postulated by poets, priests, and artists. By introducing these metaphors into the scientific discourse of embodiment, I hope to contribute to the body of knowledge that inspires investigators to reflect on the moral foundations of their enterprise. In particular, I argue that clinician-investigators should reflect upon how these metaphors contribute to the scientific objectification of subjects' bodies and how they might repair the moral and existential damage that these metaphors have done. Instead of encouraging the proliferation of an increasingly complex regulatory structure, the embodied view of respecting persons provides a pedagogical strategy for recognizing the intrinsic value of persons as body-subjects.

The scientific objectification of the human subject is operationalized through multiple discursive strategies that classify humans as primarily biological objects, define the parameters of what constitutes a healthy body, and instruct investigators on how to discipline unruly bodies so as to make them docile and passive. In clinical research, the rhetoric of reductionism serves to enable investigators to place the human body within a regime of "working objects," that is, a standardizing practice of setting certain objects as worthy of inquiry.[6] Standardizing the body eliminates important differences, making each subject indistinguishable from the next.

Inscription is the process by which the signs, symbols, and images of the human subject as working object are fixed within scientific discourse. Through inscription persons are placed within scientific discourse as objects to be investigated. In their work

[6] Lorraine Daston and Peter Galison, *Objectivity* (New York, NY: Zone Books, 2007), 19.

on how inscription into the medical chart reduces the complexity of the patient's lifeworld and story, Suzanne Poirier and Daniel Brauner describe how "[l]anguage appropriates and inevitably alters reality by *re*presenting it and making it a reflection of the speaker's (or writer's) perspective."[7] Inscription is the fixing of speech and action into writing through the use of signs and symbols. As it abstracts the ephemerality and immediacy of speech from its context, inscription in itself is necessarily reductionistic. The inscription of a reductionistic model of embodiment within scientific discourse enables investigators to ignore the intrinsic value of the subjectivity of the subject, which precludes them from fully respecting subjects as persons. While the reductionistic model is already morally problematic, inscribing this model within the discourse of medical research has led to various assaults on human dignity. Since the rhetoric of reductionism cannot allow for subjectivity, respect, recognition, and reciprocity to be inscribed, it therefore presents a distorted picture of reality. Inscription fixes a meaning to persons that is only partially accurate.

Inscription as it is described above creates a moral universe that is populated by reductive images of embodiment. These images are not simply ideas in the mind of researchers but are sometimes conveyed through actual visual images. Scientific illustrations gained widespread acceptance within of the corpus of medical evidence in part due to the development of the experimental method and its focus on the search for objective knowledge. Scientific researchers entering the field following Robert Boyle and Andreas Vesalius have inherited the ocular empiricism developed by these visionary

[7] Suzanne Poirier and Daniel J. Brauner, "Ethics and the Daily Language of Medical Discourse," *Hastings Center Report* 18, no. 4 (August/September 1988): 5.

scientists.[8] Boyle's famous debate with Thomas Hobbes concerned the value of experimental evidence in the development of theories of causation. Experimentalists like Boyle discover and craft the world simultaneously, imitating "the act of unmediated seeing" through their experimental apparatus.[9] Boyle's air pump gave rise to the visual rhetoric of the experimental method. Instead of resolving debates about the natural world through arguments, experimentalists appealed to the primacy of sight and other senses by placing collective witnessing and the communal correction of error as the primary sources of scientific judgment. Boyle's experiments also introduced the idea of verifying the credibility of an experimental method through virtual witnessing using images as mimetic devices. By sending illustrations of his air pump to colleagues in different European cities, Boyle was able to show how scientific images could facilitate distinct ideas.

Through the practice of scientific image making, investigators pattern a scientific self.[10] In the case of clinician-investigators, the images that they choose to include in their research aid in the development of their scientific persona. These images provide the viewer with insight not only into their scientific worldview, but also into their "discipline's most significant objects of inquiry."[11] The galleries and annals of medical research are filled with images that present a historical record of how investigators select images that fit an idealized norm. By drawing out how the clinical gaze inscribes bodies

[8] I will speak more about Vesalius's ocular empiricism in later chapters.

[9] Steven Shapin, *Leviathan and the Air Pump: Hobbes, Boyle, and the Experimental Life: Including a Translation of Thomas Hobbes, Dialogus Physicus de Natura Aeris* (Princeton, NJ: Princeton University Press, 1989), 18.

[10] Daston and Galison, 10.

[11] Ibid., 17.

within these images, I hope to help clinician-investigators reflect upon how the images they select fit within the rhetoric of reductionism.

Michel Foucault's notion of the clinical gaze is derived from the nineteenth-century imperative to "make science ocular."[12] As a way of seeing that underlies the clinical training of the clinician-investigator, the clinical gaze is an integral part of the process of teaching students to distinguish the normal body from the pathological one. This training privileges the power of sight over other senses. Furthermore, learning to use the clinical gaze teaches students how to transform the lived body into a scientific object by making visibility a prerequisite for scientific truth. However, this dispersion of power is only possible if it rests upon a discourse. Medical research as a set of knowledge claims about the body is possible only when what is said limits what we see and vice versa.[13] In Foucault's view, the clinical gaze "has the paradoxical ability to *hear a language* as soon as it *perceives a spectacle*."[14] Through the application of the clinical gaze, investigators are able to match pathologies to symptoms by linking the organic functionality of the body in terms of its parts and the relationships between these parts to known diseases. Applied to the healthy body, the clinical gaze peels apart the layers of skin, tissue, and bone to distinguish empirically objective knowledge about the body from the subjective experience of embodiment. Through the clinical gaze, man is identified as a biological object of study and loses his empirico-transcendental status.[15]

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[12] Michel Foucault, *The Birth of the Clinic: An Archæology of Medical Perception*, trans. A. M. Sheridan Smith (New York, NY: Random House, 1974), 88.

[13] Gary Gutting, *Michel Foucault's Archæology of Scientific Reason* (Cambridge, UK: Cambridge University Press, 1989), 125.

[14] Foucault, *Birth of the Clinic*, 108. Emphasis added.

[15] Foucault, *The Order of Things*, 350.

My concern in the sections of the dissertation that deal with images is to show the development and, where appropriate, the degradation of the moral vision of the clinical investigator during the historical periods from which these images are drawn. Through images, investigators fashion their own social imaginary, one that draws from broader cultural practices but channels these practices in a particular direction.[16] The moral vision of the modern investigator is predominantly focused on how bodies produce knowledge, not on an aesthetic grasp of the intrinsic value of the human subject. By analyzing these images according to a methodology that unpacks their aesthetic properties as well as their symbolic and historical significance, I hope to show how images may be used to train the moral vision of the investigator. By applying the methodology of a phenomenological analysis that is focused on the visual, I will show how it is possible to return to a gaze that "palpates" as well as dissects.[17] In order to draw clearly the link between morality and metaphorical vision, I will employ phenomenological theories of the visual that uncover the intrinsic value of the lived experience of the body. For example, Maurice Merleau-Ponty's phenomenology of perception begins with seeing the world as flesh, as elemental "in the sense of a *general thing*, midway between the spatio-temporal individual and the idea, a sort of incarnate principle that brings a style of being wherever there is a fragment of being."[18] For Merleau-Ponty, the visible is a "paradox of Being."[19] It is inexhaustible, found in the tendons and "flesh" that connect objects, vision, the experience of sight, and thought. The paradox Merleau-Ponty refers to is the notion that

[16] Charles Taylor, "On Social Imaginary," accessed November 25, 2012, http://blog.lib.umn.edu/swiss/archive/Taylor.pdf.

[17] Maurice Merleau-Ponty, *The Visible and the Invisible*, trans. Alphoso Lingis (Evanston, IL: Northwestern University Press, 1968), 133.

[18] Ibid., 139.

[19] Ibid., 136.

the subject is both subject and object, seer and seen, sentient and sensible. In later chapters I will show how investigators might introduce a new capacity for perceiving the Other to their gaze as they focus on an aesthetic grasp of the body-subject.

Some clarification about what is meant by the term *body-subject* is necessary if this concept is to be adequately contrasted with the idea of the body-as-object. In light of the various interpretations of the moral principle of respect for persons, the idea of the body-subject may be considered an explication of the fundamental constituents of personhood, that is, embodiment and subjectivity. Deciding who counts as a person is socially constructed out of a variety of specific moral rights, values, and beliefs. Furthermore, deciding what aspects of personhood should be respected is another challenge, one that is normally settled in favor of autonomy or self-determination. However, the term *body-subject* captures elements of being human that are prior to the social construction of identity. To this end, it describes how humans experience the world. Indeed, it places the intrinsic value of persons in their subjectivity and embodiment, not only in their capacity for autonomous decision making. It stakes out the landscape of how humans invest in their own lives and the lives of others. The body is the center of lived experience, not the transit station for sense impressions.

Living through one's body means that the world is not merely observed as an object of thought. In S. Kay Toombs's phrase, during the course of everyday experience, "I *am* my body."[20] To respect persons is to respect their moral status and right of self-governance, but prior to acknowledging their rights and powers of decision making, it is to respect them as body-subjects. Doing so requires recognition of the duality of the body

[20] S. Kay Toombs, *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient* (Dordrecht, Netherlands: Kluwer Academic Publishers, 1992), 52.

as subject and object. Body-subjects are beings that touch and are touched. This paradox of the flesh of the body as both intensely personal and part of the flesh of the world opens up my body to the body of the Other. Merleau-Ponty describes the lived body as "carnal being, as a being of depths … a being in latency, and a presentation of a certain absence"[21] This paradoxical and liminal space is captured in the hyphen between *body* and *subject.*[22] Recognizing the beauty and intrinsic value of the lived body is the first step towards learning how to fully respect persons. Signs and symbols indicating the value of the lived body surround us. They are most easily interpreted through a phenomenological lens.

Bodily intentionality is an important phenomenological concept for understanding the difference between body-subject and body-object. Body-subjects are active; their attention is drawn to being in the world. They are not simply in the world to be acted upon by others. Instead, they intentionally direct their attention to objects in the world based on a relation of "in order to."[23] In this schema of bodily intentionality, objects in the world become relevant only insofar as they relate to bodily needs. Bodies negotiate meanings and express them. Bodies act as extended selves. The experience of self flows through the entire body not as spirit trapped in matter, but as a vigorous, sensate, sentient, and vocal subjectivity. Subjectivity is experienced and expressed through the body.

Human experience is characterized by its subjectivity. Individuals experience the world differently. Although they may find themselves thrown into a world of meaning, they are also capable of living lives that are personally meaningful. Though they carry embodied knowledge drawn from cultural and social sources, humans are adept at

[21] Merleau-Ponty, 136.
[22] This same spirit is at work in Heidegger's concept of *In-der-Welt-sein* or *being-in-the-world*.
[23] Toombs, 54.

producing localized knowledge that is self-referential and self-centered. Their unique view of themselves means that they tend to resist being seen and labeled by clinician-investigators as anonymous objects in the world. In Eric Matthews's reading of Merleau-Ponty, "if the subject of experience is not a disembodied Cartesian ego but a conscious but embodied human being, then that implies, first, that subjectivity is not co-extensive with consciousness."[24] Understanding subjectivity as a form of being that extends beyond and dwells underneath the radar of consciousness is an important facet of the idea of the body-subject. In this sense, subjectivity is felt and expressed, not simply understood as one of many mental operations. The body-subject possesses an interiority that is expressed externally in that the body "inhere[s] in the world that we experience."[25] Body-subjects inhale, digest, and absorb the world. Throughout the dissertation I will argue that the investigator must learn to recognize human subjects as fellow body-subjects. To truly respect persons in the research enterprise, investigators and subjects must discover a path to intersubjectivity by crossing the paradoxical and liminal spaces between body-subjects.

Developing the capacity for intersubjectivity should involve some consideration of how participation in a research trial pulls subjects out of their everyday lives and into an uncanny space. Clinical trials are often housed in medico-scientific environments that have the look and feel of clinics or hospitals, but whose mission is radically different from the mission that drives these enterprises. Using clinical spaces for research violates the expectations that subjects have regarding how these spaces ordinarily function, causing them to become disoriented. Their understanding of the roles of the research

[24] Eric Matthews, *The Philosophy of Merleau-Ponty* (Montreal, CA: McGill-Queen's University Press, 2002), 58.

[25] Ibid.

team has to be realigned along with their understanding of how clinical spaces function. In theory, these disruptions of the lived experience would open up a space for intersubjectivity. Unfortunately, the expectations of subjects and investigators are sometimes discussed only at the beginning of the trial, which is where the dialogue often seems to end. What is needed to begin the dialogue again is for investigators to be mindful of how their own bodies embody social meanings. By doing so investigators may be able to discover more quickly how to acknowledge other body-subjects through bodily empathy. Space must be made within the enterprise itself, as well as within scientific discourse in general, for these kinds of reflections. Establishing a dialogical relationship based on a commitment to intersubjectivity is an essential feature of the more capacious sense of respect for persons I outline below.

As mentioned earlier, the normative framework outlined in the *Belmont Report* regarding the ethical concept of "respect for persons" places it first in the order of ethical principles intended to guide research with human subjects.[26] Although the *Report* indicates that the three principles are to be balanced, not ordered lexically when engaging in deliberations about the ethical permissibility of any particular issue in human subjects research, its placement at the top of the list is no accident. The history of regulations and guidelines regarding human subjects research points to a distinct emphasis on voluntary consent as an expression of a subject's autonomy. This concept is ranked first in the Nuremberg Code [27] as well as the Declaration of Helsinki.[28] The Belmont Report makes

[26] National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research.* accessed November 25, 2012, http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html.

[27] Nuremberg Military Tribunal, US v Karl Brandt, et al, "The Nuremberg Code" in *Ethical and Regulatory Aspects of Clinical Research*, eds. E.J. Emanuel, R.A. Crouch, J.D. Arras, J.D. Moreno, and C. Grady, (Baltimore, MD: John Hopkins University Press, 2003), 29.

clear the link between the concept of informed consent as a methodological constraint and the principle of respect for persons. However, the principle explicitly requires investigators to show respect for *persons*, not just *autonomy*.

Interpreting the ethical duty to respect persons as merely a prohibition against violating the autonomy of human subjects is an impoverished view of what this duty really should require. The focus on consent "divert[s] attention away from the issue of experiments per se. It allows for humans to be used in the name of science in its quest to 'discover the secrets of nature' provided that they are willing scientific objects."[29] Yet, the Belmont Report explicates this duty in precisely this fashion, which explains why respect for autonomy has become such a popular concern in the bioethics literature regarding human subjects research. I argue that respect for autonomy, while necessary, is not sufficient for a capacious sense of respect for persons. Instead, what is needed is an "embodied view" of respect for persons. The Kantian notion that persons are to be respected because of their rationality is too narrow to adequately address all of the issues relevant to human subjects research. Respect should not be given or withheld based on one's capacity for rationality, but should be automatically bestowed on human beings because of their inherent worth as beings deserving of "recognition respect."[30] By recognition *respect* I am referring to Dickert's notion of respect as an ethical obligation that is based simply on the recognition of shared humanity. To take this notion of *recognition* a bit further, the embodied view calls for a recognition of the body as an

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[28] World Medical Association, "Declaration of Helsinki" in *Ethical and Regulatory Aspects of Clinical Research*, eds. E.J. Emanuel, R.A. Crouch, J.D. Arras, J.D. Moreno, and C. Grady (Baltimore, MD: John Hopkins University Press, 2003), 29.

[29] Jordan Goodman, Anthony McElligot, and Lara Marks, eds., *Useful Bodies: Humans in the Service of Medical Science in the Twentieth Century* (Baltimore, MD: Johns Hopkins University Press, 2003), 13.

[30] Neal W. Dickert, "Re-Examining Respect for Human Research Participants," *Kennedy Institute of Ethics Journal* 19, no. 4 (December 2009): 311-338.

outward expression of the personhood of the subject. Recognition in this sense demands that investigators show discernment about their access to subjects' bodies, that they show their gratitude for the temporary gift of access to the body of a stranger, and that they treat subjects' bodies not simply with respect, but with reverence. While this argument might sound circular, it rests on a foundation that is more stable than basing respect for persons on their capacity for autonomy and rational decision making alone. Autonomy is only one, albeit important, feature of personhood. There are at least two dimensions of personhood that have traditionally been neglected by the infatuation with autonomy: subjectivity and embodiment. Somehow in all this talk about autonomy the body-subject has been neglected, even though it is at the heart of all of the principles in the Belmont Report.

According to James F. Childress, "the principle of respect for autonomy is ambiguous because it focuses on only one aspect of personhood, namely self-determination, and defenders often neglect several other aspects, including our embodiment."[31] Self-determination does not arise out of a vacuum, but from a network of social relationships and a lifetime's worth of accumulating embodied background understandings and negotiated footings. One might argue that a more fundamental feature than our capacity for autonomy is the human capacity for experience as an embodied subject. Subjectivity precedes and underlies the capacity for autonomous thought and action. Showing respect for the subjectivity of the Other may be demonstrated in several

[31] James F. Childress, "The Place of Autonomy in Bioethics," *Hastings Center Report* 20, no. 1 (January- February 1990), 13. A truly fascinating statement, since M. Therese Lysaught notes that Tom Beauchamp and James F. Childress are largely responsible for subsuming the principle of respect for persons underneath the principle of respect for autonomy. See M. Therese Lysaught, "Respect: Or, How Respect for Persons Became Respect for Autonomy," *Journal of Medicine and Philosophy* 29, no. 6 (December 2004), 675.

ways. By showing respect for the body of the Other, one shows respect for his individual subjectivity. Without considering the body of the Other as sacred, individual, and demanding respect, ethical norms governing research on the body are incoherent.[32] Though he does not use these terms, Larry Churchill clearly has a similar thought in mind when he suggests that respect for persons "should be removed as the first principle [in the Belmont Report] and discussed in the introduction to the principles section of *Belmont* as the guiding vision for everything that follows."[33] However, Churchill does not provide any suggestions on how this "ontological claim" about how one should regard persons should be understood, beyond some remarks about its resemblance to Kant's second formulation of the categorical imperative.[34]

A principle of respect for persons that focuses on embodiment and subjectivity goes beyond decision making. Respect for autonomy is relevant only when choices are being made by the subject. After signing the consent form, the only other major choice that the subject makes is whether to continue the study. Treating persons with respect demands more than just respecting and protecting their right to make their own decisions. The embodied view speaks to how subjects should be recognized, valued, and not merely objectified. This duty holds throughout the course of the trial, not just when choices are being made.

According to the embodied view proposed here and elucidated throughout the dissertation, respect requires, at minimum, recognition of the individual as intrinsically valuable. It does not require an appraisal of the individual's character or of those

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[32] Larry R. Churchill, "Toward a More Robust Autonomy" in *Belmont Revisited: Ethical Principles for Research with Human Subjects*, eds. James Childress, Eric Meslin, and Harold Shapiro (Washington, DC: Georgetown University Press, 2005), 117.

[33] Ibid., 118.

[34] Ibid.

particular traits that make individuals worthy of respect. This notion of respect allows it to be seen as a mood or a general way of approaching human subjects rather than as a set of structured relationships based on particular aspects of particular persons according to which they must be respected. Research subjects should be respected as a subset of persons who have agreed to participate in a particular human endeavor, one that involves risk, uncertainty, and the potential for harm as well as benefit. Investigators need not and should not base their respect for persons on particular traits of those individuals. They should respect the fact that human volunteers are body-subjects who should be encouraged to express their subjectivity, but investigators should not be required to form some minimal account of respect based on certain aspects of research subjects that they find valuable. This minimal account of recognition does not require the kind of intimacy, vulnerability, and interdependence necessary for a deeper ethic of care as an extension of respect. However, it does require an aesthetic attunement and attentiveness to the body of the Other that works in conjunction with the scientific focus on the data being gathered from the body. In the next chapter, and in more detail in chapter 4, I will further explain what recognition respect entails.

In order to uncover the foundational images of the embodied view of respect for persons, I will undertake a phenomenological analysis of the discursive strategies that have shaped the moral vision of investigators. Phenomenology is useful because it uncovers the value of subjective ways of knowing and the usefulness of the knowledge that subjective experience produces. Phenomenology helps to uncover the experience of embodiment, which provides insights that are integral to the expansion of medical knowledge about the body. While the language of phenomenology can be dense, obscure,

and esoteric, a phenomenological analysis has several advantages that outweigh the initial challenges one might face in understanding its methodology. First, phenomenology is the philosophical study of subjective experience. As a methodology, it offers resources for describing subjective experience that are helpful for uncovering the meaning of embodiment. For phenomenologists, there is no separation between the body and the person during the lived experience of everyday life. This is especially true for healthy persons. Second, it also offers a means for interpreting aesthetic experience that supplements the traditional language of art criticism. A phenomenological analysis of aesthetic experience helps make connections between the body as aesthetic object and the body as scientific object. Third, phenomenology is adept at uncovering the tacit assumptions and perceptions on which our relationships with other persons are built. Recognizing the lived experience of the Other is the first step towards respecting them as persons. In the field of medical humanities scholarship, most phenomenologists are concerned with the subjective experience of illness. However, I will use the tools of phenomenological analysis to analyze and create images of the subjective experience of embodiment, since this facet of life is central to the experience of research subjects. These tools include the conceptual frameworks necessary for investigating the experiences of perception, sensation, and introspection. In particular, I will focus on the experiences of the lived body, body-as-object, body as scientific object, and uncanny body. Phenomenology is helpful in the research context because it can be used to trace the link between how one sees and how one acts, as I will show throughout the dissertation.

In chapter 1, I outline the four body schemas mentioned above, with a special emphasis on the lived body. Using a narrative that combines the experience of several healthy research subjects, I investigate the possibility of intersubjectivity as a product of engagement with the body of the Other. The clinical space as a catalyst for reflection on the meaning of embodiment serves as the setting for this narrative. In selecting this narrative, I acknowledge that not all clinical trials or clinical studies using healthy subjects will occasion this kind of reflection. Nonetheless, the plausibility of this scenario is not limited by the duration or invasiveness of the study. Instead, the depth of the experience of objectification is heightened at a rate that is directly proportional to those factors. The historical episodes I cover in chapter 2 are an illustration of this claim.

Using historical episodes that demonstrate how subjects' bodies have been objectified by investigators, I trace the historical development of the mechanical, industrial, and agricultural metaphors mentioned above. In the phenomenological analysis of each episode I show how the rhetoric of reductionism shaped the moral vision of investigators as well as the existential and moral consequences of objectification. In particular, I discuss a variety of experiments using healthy subjects, primarily prisoners and soldiers, that demonstrate how a corrupted moral vision can lead to serious violations of human dignity and a total disregard for the intrinsic value of persons.

As alternatives to the metaphors discussed in chapter 2, I begin chapter 3 by describing metaphors that speak to the lived experience of embodiment. The idea of the body as a temple has its roots in Christian scripture, yet its influence was felt throughout the intellectual history of western humanism. Poets, priests, and anatomists used this metaphor as a means for investigating the corporality of the body in the search for the

divinity they believed was locked within its flesh. From this investigation of the sacred and profane I then move on to discuss several metaphors that I place within the foundational image of the body as an "America." This image is translated into metaphorical visions of the body as wilderness, as map, and as garden. It is in this chapter that I introduce a metaphor that has the possibility of bridging the gap between reductive views of the body and those that recognize its intrinsic value.

The moral framework that supports the embodied view of respect for persons is outlined in chapter 4. In this chapter I describe the metaphor of the body as music and suggest that its moral and epistemic content may be sufficient for capturing the lived experience of the body as well as the experience of the body-as-object. This metaphor successfully navigates these mutually exclusive concepts, thus providing the kind of broader moral vision thought to be necessary for a more capacious sense of respect for persons. Using Emmanuel Levinas's theory of the face-to-face encounter to flesh out the normative implications of this metaphor, I argue that the imperative to respect persons is enlarged through a view of research ethics as improvisational.[35] In the final section of this chapter I provide an aesthetics of the body that serves as the phenomenological foundation for an ethics of recognition, reciprocity, and respect.

In an intervening section of the dissertation that I am calling the "Interlude," I provide a summary of each of the metaphors described in the previous chapters. I also provide a brief critical assessment of the epistemic and moral content of these metaphors. This assessment will result in a systematic analysis of the strengths and weaknesses of

[35] Emmanuel Levinas *Totality and Infinity: An Essay on Exteriority*, trans. Alphonso Lingis (Pittsburgh, PA: Duquesne University Press, 1969).

each metaphor. In so doing, I will show how some of these metaphors might be incorporated into the research ethics curriculum and why others should be discarded.

In chapter 5 I outline an educational curriculum through which the aesthetic attunement outlined in chapter 4 might be integrated into the training of clinician-investigators. I argue that this kind of aesthetics is not primarily concerned with appreciating beauty or with developing a moral psychology, but is intended simply as a method for learning to see the Other. This aesthetic training is steeped in the disciplines of the medical humanities, including visual arts, literature, music, and theater. I close this chapter by returning to the story of Nikita found in chapter 1 and provide some suggestions as to how an ideal investigator might demonstrate respect for her as a person.

I conclude the dissertation by discussing how the educational curriculum that I outlined in chapter 5 might be applied within the paradigm of translational research ethics. There appears to be a particular need for an educational model that address the core clinical competencies in which all translational researchers must be proficient. Furthermore, there is evidence that suggests subjects who are involved in an investigator-subject relationship in which they feel respected are more likely to continue participating in the clinical research enterprise. I also elaborate on the findings of several studies that highlight the importance of a spirit of collaboration within the investigator-subject relationship. Finally, I speculate on the need for more research on the subjective experience of human research subjects as well as the need for a model of respect that can address ethical problems that arise during the course of community research programs. My contention in the final portion of the conclusion is that the capacious sense of respect

for persons I outline below will be able to address these and other challenges that confront clinician-investigators.

Chapter 1: The Phenomenological Foundations of Respect for Persons

In this chapter, I will focus on the notion of the lived body as the fundamental source of meaning making for persons as well as the foundation for the moral obligations owed to persons. This concept of the lived body is central to the thesis I am proposing and needs to be placed within the context of the experience of human research subjects who are enrolled in a clinical trial. However, the lived body is only one of several body schemas that present themselves to consciousness. In this first section I will briefly outline the transformation that occurs as subjects move from the experience of the body as lived to the experience of the body as scientific object. In later sections I will explore this transformation in more detail. In this chapter I argue that for healthy subjects who are enrolled in clinical trials or studies, the experience of transitioning from the lived experience of health and freedom to the experience of being used as a scientific object while confined in a clinical space can be somewhat traumatic. When a subject enrolls in a research trial, a transformation occurs in the way that the body is perceived. Entering into the clinical space as a research subject brings to the foreground the experience of the body-as-object. This way of seeing one's body as an object causes the subject to reconsider his embodiment as well as his sense of self.[1] Although other aspects of life may cause this kind of reflection, the objectification of the body in the space of clinical research is unique in that this objectification makes the body appear as something that is

[1] See Roberto Abadie. *The Professional Guinea Pig: Big Pharma and the Risky World of Human Subjects* (Durham, NC: Duke University Press, 2010); Anonymous,"22 Nights and 23 Days: Diary of #1J, Drug Study Subject," http://www.guineapigzero.com/23days.html.; Mikita Brottman, "I Was a Brain Slave," http://www.guineapigzero.com/brainslave.html.; and Robert Helms, *Guinea Pig Zero: An Anthology of the Journal for Human Research Subjects* (New Orleans, LA: Garrett County Press, 2002).

entirely for-the-other. To enter into the clinical space is to initiate a relationship of instrumentality. Though this relationship is consensual, subjects' bodies are nonetheless used only for knowledge. Their knowledge of their bodies is irrelevant if it cannot be quantified and tested objectively. The purely instrumental use of the body obscures the lived experience of embodiment. Over the course of this transformation, wherein the body is recognized merely as an object, the lived body is seen as an uncanny body. It becomes an object that is strangely familiar, yet not entirely recognizable as oneself. This experience of the uncanny is exacerbated by the *scientific* objectification of the body. To summarize the progression, which is not necessarily linear or sequential, within the space of the clinical research enterprise the body is apprehended as lived body, object body, uncanny body, and scientific object. Tracing out how investigators can learn to recognize these phenomenological transformations is the first step towards developing a capacious sense of respect for persons. Investigators are obligated to show the respect and recognition that is due to the lived experience of the human subject.[2] Investigators must learn to moderate the objectification of the person by attending to the experience of the lived body of the subject as well as their own lived experience.

I will preface my remarks on what it means to seek a phenomenological foundation for respect for persons by first explaining what to expect from a phenomenological view of the person, especially with regards to how phenomenology reveals certain hidden dimensions of embodiment. Drawing from the pioneering work of Edmund Husserl, phenomenology presents itself as a philosophical discipline that seeks to uncover the essence of experience. Husserl's transcendental reduction calls for

[2] The moral foundation for respect as an ethic of recognition and reciprocity grounded in the lived experience of the body will be treated in much greater detail in chapter 4.

phenomenologists to bracket the assumptions about the world that science and metaphysical thinking provide in order to understand the nature of experience itself. Through bracketing, the transcendental reduction develops skills of reflection on everyday experience that illuminate certain essential features of experience. Outside of this reflective attitude, in what Husserl calls the "natural attitude," persons do not question their everyday assumptions about the world and the objects, events, and relationships that constitute it. More specifically, in people's everyday focus on projects and tasks they do not attend to the essence of the world or the conscious contemplation of experience itself. In the natural attitude, that is, in lived experience, the person experiencing is not conscious of his ego as something that stands apart from the world nor is he conscious of his body as such. Instead, the world appears as given.

To explain to others what it means to understand the world as given and the intentionality of the body, I often use my own subjective experience as an example. This rhetorical strategy has the benefit of helping me internalize the conceptual framework of phenomenology while simultaneously demonstrating its explanatory power. Both my subjective experience of the world and the world itself are given in the sense that they are immediately present to my consciousness. Although I may often perceive the world unreflectively, it is clear that at any particular moment during my waking life, I am conscious of some object, thought, or event.[3] In the course of my day, I may choose to focus my attention on a variety of phenomena. In fact, my attention is almost constantly shifting from one experience to another. My subjective experience of these shifting foci illustrates the concept of "givenness" in that their variety and plenitude suggest that a

[3] This consciousness of something is known as *intentionality*. This concept will become quite important for the study of embodiment.

multiplicity of possible meanings exists within the meaning-structure of the world. It is only upon reflection that these meaning-structures are uncovered. More importantly, it is upon reflection that the body reveals itself as an object. In the next section, I have constructed a fictionalized account compiled from the experiences of real human subjects as documented in various weblogs, anthologies, and e-zines. My intention in crafting this narrative is to use the phenomenological concepts discussed in this chapter to unearth the lived experience of human research subjects. By introducing this narrative account, I hope to provide insights into how the quality of the investigator-subject relationship plays a role in determining whether or not subjects feel that they have been fully respected as persons. The experience of the healthy human subject I have introduced below as Nikita is not meant to be generalized to all healthy subjects. However, her story is integral for understanding the subjective experience of embodiment as it is transformed by participation in biomedical research.

EXPLORING THE LIVED EXPERIENCE OF HEALTHY SUBJECTS

Nikita is a twenty-five-year-old woman who enrolled in a sixty-day study of the effects of microgravity on the human body, which required that she remain in bed for the duration of the study.[4] As an avid fan of space exploration and a bona fide "Trekkie," she was enthusiastic about signing up for a protocol designed by NASA to test countermeasures to prevent bone density and muscle loss as a result of extended periods of weightlessness. Prior to her enrollment she had to endure several weeks of screening, which included a battery of intense physical and mental tests. At the end of this period,

[4] The following narrative is compiled from and inspired by a variety of sources including selections from Anonymous, "22 Nights and 23 Days: Diary of #1J, Drug Study Subject."; Mikita Brottman, "I Was a Brain Slave."; and Heather Archuletta, *Pillow Astronaut* (blog), http://pillownaut.blogspot.com.

she was cleared to participate based on her excellent health. As part of the informed-consent process, she was told that she would face moderate risks of physical impairment following the study, a difficult and painful period of time adjusting to the microgravity, and constant monitoring to ensure that she did not violate the protocol by sitting up. On the day that she arrived to begin her study, she was only allowed a small number of personal items with which to adorn her living space for the next six months. For the purpose of confidentiality, her name was removed from all documents referring to her participation in the study, and she was given a reference number in its place. In anticipation of her first day confined to bed, Nikita began to reflect on the strangeness of her situation. The nurses and investigators on the unit to which she had been assigned referred to her and her fellow subjects as "flight analogs." This appellation seemed curious to Nikita. On the one hand, it seemed to suggest to her that she was being regarded by the investigators in charge of the protocol as a living mathematical model that was simply there to provide data that actual astronauts could not provide. On the other hand, although she knew she would never qualify to become an astronaut, becoming a "pillownaut" seemed just as good.[5] As she lay in bed that first night, Nikita reflected on her history up to this point. By her own account she was a typical Type A personality. She was used to an active lifestyle that involved extensive traveling in exotic locations. Spending two months reclining seemed like the perfect opportunity to enjoy a grand adventure in self-mastery, take some needed time off, and, most importantly, aid the space program. However, she panicked at the thought that she would not be able to do anything for herself in the manner in which she was accustomed. "What would it really

[5] Heather Archuletta, "This *IS* My Happy Face," *Pillow Astronaut* (blog), July 30, 2008, http://pillownaut.blogspot.com/2008/07/this-is-my-happy-face.html.

be like to lie around like an animal in the zoo?" she wondered as she slipped underneath the covers.

As the first morning of her second day of confinement to bed arrived and the sun streamed through the windows, Nikita thought about how she would not be able to enjoy its rays, as doing so would violate the protocol. "So many things would violate the protocol," she thought, "yet it will be worth it. Not only will I make some decent money, but I'll be helping to advance aerospace medicine." Still, she was having difficulty getting used to lying down all the time. Normal everyday activities like typing on her laptop had to be modified to accommodate her new perspective on the world. Her hand had to dangle in the air at odd angles in order to use her computer mouse and she felt a tingling sensation in her wrists every time she clicked on a Web page. The night before had been uncomfortable as well, as she struggled to sleep. As the morning dragged on, she found herself constantly fighting the natural urge to move, stand, and be active in the world. Her body seemed to weigh her down even though she was supposed to be modeling weightlessness. She wondered whether she was doing the right thing and wished that someone would speak to her about her experience—someone who knew what it was like from a clinical standpoint, but who wouldn't get bogged down in trying to diagnose her complaints as merely indicative of psychological distress. The last thing she wanted was to be treated as another potential dropout.

As Nikita's reflections indicate, prior to encountering the gaze of the Other within the clinical research enterprise, in what might be called the prereflective givenness of everyday life, there is no distinction between body and self. In the everyday life of the

potential human subject, the body is "absently available."[6] It is not possessed by the self, but is instead lived through. The body is a silent partner in subjects' attention to their projects in the world. Blood flows to the organs, food is digested, invaders are repelled, and yet the self remains largely unaware of these functions. In Jean-Paul Sartre's phrase, "my body as it is *for me* does not appear to me in the midst of the world."[7] In the case of Nikita, her body does not appear to her as she is living through it as an object constituted by cells, blood, tissues and organs. In other words, Nikita does not see her body as others, especially clinical investigators, do. She cannot have an experience of the duality of the body, according to Sartre. It cannot be an object for her and lived through simultaneously. Other scholars have disputed this point. For example, Stephen Burwood suggests that an experience of the duality of the body is actually an experience of the uncanny, a topic that I will discuss later in this chapter. Before engaging in this debate about the duality of the body as lived and the body-as-object, I will describe the essential features of the lived body as they have been uncovered by a phenomenological analysis.

In her work on the phenomenology of the illness experience, philosopher S. Kay Toombs lists several key features of the body as lived: *primary meaning, bodily intentionality, contextual organization, gestural display*, and *body image*.[8] Some of these characteristics and capabilities enable the body to be interpreted by others as well as offer the possibility of knowing and relating to them intersubjectively. Other capabilities establish the body as the focal point of our being in the world. In this respect, they establish a point of view that is unique to each individual. Each lifeworld is constructed

[6] Shaun Gallagher, "Lived Body and Environment," *Research in Phenomenology* 16, no. 1 (1986): 161.

[7] Jean-Paul Sartre, *Being and Nothingness: An Essay on Phenomenological Ontology*, trans. Hazel E. Barnes (New York, NY: Philosophical Library, 1956), 279.

[8] Toombs, 52-56.

and identified as one's own because it is known through the body. Knowledge is not simply gleaned from the world as if it and the body could be separated, but is lived through the body.

Understanding the dynamics of the lived body in terms of how it is lived through are important for showing how this lived experience is affected by the environment. As the primary source of meaning in the world, the positioning of the body within that world establishes a unique style of living in the world. This style is expressed internally to consciousness as body image or body schema. Other scholars, like Shaun Gallagher, have chosen *body schema* instead of body image to describe how the body is positioned within the environment in relation to projects.[9] This schema is always subject to change along with the environment and the physiological dynamics of the body. In illness the body schema may be radically altered due to the way that illness limits a sick person's projects in the world. A more subtle transformation occurs during the subject's participation in clinical trials. This transformation significantly alters the way in which the body appears to the self.

To draw again from Nikita's experience on the space protocol, it is clear that bodily intentionality is an integral part of the lived body. Bodily intentionality is the notion that bodies are always directed towards some kind of project in the world.[10] Upon reflection, Nikita's projects in the world are constrained by the way that her environment is configured. Her desire to manipulate her environment is curtailed by the limitations of the protocol such that any vertical motion of her body must be coordinated with the research team. She may exercise, but only in the manner and at the time prescribed by the

[9] Gallagher, 157.
[10] Toombs, 53.

protocol. Since her bodily intentionality is constrained and her projects are limited, she is forced to channel this intentionality into activities that do not involve the entire body. For example, she is able to watch movies but not go to the theater and enjoy the experience of being immersed in that environment. She may listen to music but not attend live concerts. Furthermore, as she continues in the protocol, her senses of touch and proprioceptive awareness will decline, making some kinds of intentional activity severely circumscribed. From these examples, it is reasonable to assume that some essential elements of the lived body are missing or constrained by Nikita's participation in the study.

The experience of the body as lived within a lifeworld populated by other body-subjects makes possible an understanding of the movements and the significance of gestures made by other bodies. Indeed, this sense of intercorporeality through the recognition of the gestures of others is the ground of the possibility of intersubjective understanding and being-with-others. In an individual's everyday life he makes numerous gestures, mimics the gestures of others, and sees these gestures as reflections of himself prior to any cognitive understanding of their meaning. This phenomenon is often referred to as reading the "body language" of the Other. For example, if I see someone who looks familiar extending her arm upwards and shaking her hand at the wrist, I am alerted to her gesture and am able to place it against my background knowledge of bodily forms. Using this knowledge, which I gained by observing the movements and bodily placement of others, I am able to recognize that she has seen me and is beckoning me over to her. Of course, there are a myriad of more subtle contextual cues that signify the emotions of others that also must be read in order to permit an intersubjective understanding of the world as shared. In all cases, I am able to truly see the Other only if I can "perceive his

body as a totality"[11] in context. During these moments of recognition and interpretation, I am not conscious of my own body as an object responding to other objects but am able to recognize the gestures of others because I have incorporated them into my own lived experience. I recognize the Other because of my familiarity with a variety of contexts in which I have seen other bodies. Through this understanding of the contextual ground upon which bodies move I recognize the body of the Other as a "systematic totality of intrinsic references or functional significances"[12] and therefore regard my own body also as a totality. In the everyday mode of being in the world, both the body of the Other and the lived body are lived as this totality. In other words, the body as lived is ignorant of its dual nature as subject and object. Although I can never approach the Other's body as it is for him, I can perceive the instrumentality of my own body.

As a material object like other material objects in the world, the body-as-object is constructed as such by its instrumental relations with other objects in the world. In terms of these relations, the body is "at once a tool objectively defined by the instrumental field which refers to it and at the same time the tool which we cannot *utilize* since we should thus be referred to infinity. We do not use this instrument, for we *are* it."[13] The body can be an instrument that one uses or used by others as an instrument. However, Sartre denies that we can be aware of ourselves using our bodies as instruments because we cannot be both a subject and an object at the same time. As an instrument, the body makes the world—that is, the world exists because of the need for possibility-making instruments. The instrumental value of the body may be used to benefit oneself or may be used to

[15] Ibid., 57.
[12] Ibid., 55.
[13] Sartre, 324.

benefit others, but it is always tacitly present as the primary source of the lived body's relationship to the world.

Although on occasion the body reveals its instrumental value, we do not perceive ourselves as Cartesian egos locked within a machine-body that resolutely obeys our commands. Instead, our attention is fixed upon the world we inhabit and the tasks that we are driven to perform. Sartre's term for this mode of living through the body is "surpassing towards my own possibilities."[14] The body is thus something that is surpassed, and to some degree suppressed, in my attention to projects in the world. However, this attention may be captured and redirected at the body when these possibilities become limited in some fashion.

Given that at any time the lived body may be transformed into the body as object, it remains to be seen how the unity of the lived experience is maintained and how it may be disrupted. This possibility lingers within the natural attitude as prereflective awareness or tacit knowledge of the body as a biological object. In this sense, the self is aware at a prereflective level that the body is not only lived but also necessarily an object like other biological objects. This recognition occurs within the margins of consciousness as a vague sense that the lived body is "an intertwining of intentionality and materiality, subject and object."[15] This intertwining can unravel if one's lifeworld is disrupted by events or ideas that persuade the self to reflect upon its materiality. In Burwood's phrase, "the doubling of the body, the 'splitting of the phenomenon' into two abstractions takes

[14] Ibid., 304.

[15] Drew Leder, "Medicine and Paradigms of Embodiment," *Journal of Medicine and Philosophy* 9, no.1 (February 1984): 28.

place only in an objectifying reflection or observation."[16] This kind of reflection may be catalyzed by the subject's participation in a clinical trial. The depth and intensity of this reflection vary with the invasiveness and the duration of the clinical trial.

UNRAVELING THE INTERTWINING OF BODILY SUBJECTIVITY AND OBJECTIVITY

Upon reflection, the body is revealed as the mediator between the self and the world of its concern. This reflection may be occasioned by any number of events, but for the purposes of this dissertation, I will concentrate on the experience of participating in a clinical trial. There are three elements of subjects' participation in clinical trials that provide occasions for reflection on the body-as-object. They all center on the face-to-face encounter between the subject and the research team, although the third concerns the contextual organization of the clinical space while the other two deal specifically with how subjects and investigators see one another. The first and primary catalyst for the apperception of the body-as-object is realized in the gaze of the Other.[17] In the case of the human research subject, the investigator or a member of the research team directs this objectifying gaze. Subjects make judgments about how the research team sees them based on how they are treated and reflect that objectification in their perception of their own bodies. Sartre describes this phenomenon as the "Look" of the Other.

The Look as Sartre describes it is the objectifying gaze of the Other. As it settles upon my body, it identifies my bodily intentionality while masking the world as I see it and limiting my possibilities. The Look of the Other redefines my intentionality as "an

[16] Gallagher, 140.
[17] Toombs, 58.

obstacle and a means as all instruments are."[18] In the process of redefining my body as an obstacle, the Look of the Other reveals my instrumentality to me. As Sartre explains, "by the mere appearance of the Other, I am put in the position of passing judgment on myself as on an object, for it is as an object that I appear to the Other."[19] The revelation of the instrumentality of the lived body which uncovers the materiality of the body-as-object and transforms my lived body into my body as an object is a rhetorical project initiated by the Look. I know that the Look of the Other objectifies because I am able to return the Look and in so doing objectify the Other.

In one of the more poetic passages of *Being and Nothingness*, Sartre describes how in viewing the Other as object it appears as though "suddenly an object has appeared which has stolen the world from me."[20] To return to Nikita's story, from her point of view, the research nurse who appears on the horizon to withdraw a blood sample stands out as a figure with bodily intentionality. He is an object unlike other objects. As he enters the frame of vision, he skews temporal, spatial, and instrumental relations towards himself. These relations escape Nikita. For her, it must seem as if another heavy object has entered her solar system and has begun to distort the fabric of space-time. The instrumentality of the world as it is for her has changed with the appearance of the Other. However, her place as a center of instrumentality is made apparent only by the "revelation of [her] being-as-object for the Other," since it is only through this revelation that she "must be able to apprehend the presence of [his] being-as-subject."[21] In other words, the nurse sees Nikita as an object, which means that he must also be a subject

[18] Sartre, 264.
[19] Ibid., 222.
[20] Ibid., 255.
[21] Ibid., 256.

since to see an object means to inhabit a world, which is only possible if one is a subject. Objects do not live in worlds; they may not "have" worlds in the way that subjects do. Thus, on the one hand, the objectification of the Other through the return of the Look is necessary in order to reveal Nikita to herself as a body-subject. Yet, on the other hand, there is a tension in this regime of intentionality and instrumentality in that the Look of the Other shines a light on how possibilities and freedom are limited by conditions of instrumentality. In Sartre's work there is a certain tension between a view of the Other as constitutive of my lifeworld but also as a threat to my lifeworld and my projects. This tension is magnified by the relationship of instrumentality upon which the subject-investigator encounter is always already founded. In other words, the intensity of the Look is magnified by the clinical gaze and the research imperative.

In Sartre's view there is always the danger of becoming "the instrument of possibilities which are not my possibilities … and which deny my transcendence in order to constitute me as means to ends of which I am ignorant."[22] This danger emerges as clear and present during and after the informed consent process. Although consent is given, it is never a settled question of how subjects will understand their experience of participating in the trial or how this experience will change according to how they are seen and treated by the research team. The trial conditions may be specified in the protocol, but the actual conditions as they develop each day may be beyond the capacity of the protocol to predict or account for.

In the Look, the Other is not given as an object because it is the subjectivity of the Other that makes the Look possible, but upon returning the Look the Other is objectified

[22] Ibid., 268.

as a defense against my being-for-the-Other.[23] In Sartre's view, this Look does not require that one physically confront the Other. One may be completely alone and still subject to the Look of the Other. However, in the clinical space the Look of the Other is inescapable. Even when not physically in the presence of the Other, the clinical gaze as an extension of the Look is omnipresent. This is literally true in Nikita's case, since she is constantly monitored either by video cameras or the clinical staff. Her bodily apprehension of the Look is the catalyst for its objectification of her and her subsequent objectification of the Other through the return of the Look. Even if the Other does not physically observe her and she simply feels like the Other is watching, it still is a bodily apprehension that triggers this thought. The Other can only see her if she is a body. So, in Nikita's world, she is already aware of her being in the world before the Other finds her.

Reflection on the instrumentality of the body is also triggered by the resistance of the body to the intrusion of the scientific instruments. This intrusion need not involve penetration of the body's perimeter, but may be aroused by the placement of the body within the clinical space where intrusion is a possibility. The placing of electrodes on Nikita's chest, arms, and neck readies her body for scientific measurement. Surfaces of her body are occupied by instruments, which transform the spaces around her body from liminal and neutral to colonized clinical spaces. The distinction between her body and the instruments of medical research diminishes to the point that the two are fused. Not only is her body seen as an instrument, but it is also used as an instrument to see itself. Touching the electrodes on her body brings forth a sensation of alterity. While inside the sterilized space of the sealed package, these instruments are apprehended as objects like any other.

[23] Ibid..

Their proximity is of little concern to her as they are not instrumentally related to the possibilities of the body. They are owned by others while Nikita owns both the proximal and distal spaces of her body. But once they are applied to the skin they begin to colonize her space and she becomes part of the machinery of science, though only after a period of resistance. The body monitors itself to protect against invasion, so that neutral zones around the body act both as buffers against invasion as well as potential spaces for bodily intentionality.

As Nikita began to adjust to life on the flight analog unit, she thought to herself, "What a strange yet familiar space this is!" As it is housed in the same hospital where deathly ill patients are treated and babies are birthed, the flight analog unit mimics the arrangement of the cold, sterile, and purely functional style that is hospital-grade minimalism. Aside from the various space-related paraphernalia that cover the walls and ceiling with portraits of astronauts and posters of various space shuttles, the décor is indistinguishable from any other unit in the hospital. Magazines line the common room as the television spouts the latest headlines. Nurses and physicians weave in and out of subjects' rooms, taking measurements and writing orders. However, there are significant, yet subtle differences between this space and the therapeutic spaces that surround the research center. There are no families anxiously pacing in the waiting room, straining to gather any bits of information that may indicate the health status of their loved ones. There are no chaplains attending the bedside of the gravely ill or intoning the last rites over the weakened frames of the faithful. Instead, there are research coordinators summarizing lengthy consent forms filled with scientific explanations and legalistic jargon for the daring few who wish to enroll in a trial. Physicians insert needles into the

legs of volunteers for biopsies while research nurses hand others sugary drinks to test their glucose tolerance. If, as Sartre suggests, objects indicate the presence as absence of the body of the Other, then where in all of this scientific ephemera disguised as medical paraphernalia might we find the lived body of the subject? There are no indications of her presence outside of her physical body. Apparently, she is not at home as there are no signs with which to decipher her being-there. Her body has become lost in the wilderness of the research enterprise, temporarily leased to the ownership of the Other.

In Gallagher's view, the body is "experientially unowned" in the lived experience of the subject.[24] It makes little sense for one to say that he owns his body if he is not even aware of it during the course of his everyday attention to tasks in the world. However, if ownership is temporarily transferred—or at least permission to cross the boundaries of the body is granted—to the investigator, it seems that the opportunity for the objectification and the commodification of the body is also opened up to the investigator. In other words, the body is revealed as an object both in the Look of the investigator and in the decision to willingly consent to enter into the realm of the investigator. In the sense that the body becomes something alien where ownership is claimed by the investigator, the body is thematized as Other. This temporary loss of ownership is amplified by the body losing its "equilibrium with the environment."[25] In the everyday course of being-in-the-world, the lived body is surpassed in Nikita's choice to pursue her possibilities within the world. This is the essence of her freedom. However, when her possibilities become, albeit only temporarily, dead possibilities, her freedom has been curtailed. Such is the case when her world becomes the world of the Other. This happens as a result of her

[24] Gallagher, 147.
[25] Ibid., 152.

body as it appears to her disappearing in the relation of her body as it is seen by others. Of this relationship more needs to be said, especially as it pertains to how the essence of the lived body changes as a result of participation in a clinical trial.

Placed in the clinical space at the mercy of the clinical gaze, the body schema of the lived body loses its intentionality. Possibilities which were once active and real because of the way the body is surpassed in its directedness towards these possibilities become dead possibilities. As an embodied subject, the implications that changes in Nikita's being-in-the-world have for her body are also passed on to her. Instead of being surpassed, the body-as-object suppresses the self and reveals the inescapability of embodiment. Being a particular body in a particular lifeworld means being fated to suffer whatever trauma affects this particular body. Just as the subject's world is constricted by the boundary conditions of the protocol, so too does the body place limitations on the freedom of the self, now revealed as something other than the body, to escape the body. Part of the transformation of the lived body to the body-as-object is a change in temporal and spatial relationships, which dictate the limits of bodily intentionality.

With regards to how the body perceives the contextual organization of the clinical space, it is clear that the lived body perceives the gestures of the Other only insofar as these align with a background containing other known features of the world and other movements of the body. In an alien environment where the dual purpose of the instrumental relationships makes recognition of the ground of the body of the Other problematic, the capacity for the lived body to maintain its relationship with the ground of its own being is diminished. Simply put, potential subjects may not be sure how to act in the clinical space because their assumptions about the significance of the gestures of

the bodies in this space are incorrect.

As mentioned above, to the novice subject this context is alien. It is dressed in clinical drag but its purpose is not to heal. The contextual grounding of the bodies involved in the enterprise is placed on different foundations. For example, the research nurse in charge of Nikita on the surface appears to be someone whose primary duty is to keep subjects comfortable. He may even excel at this task, perhaps even to such a degree that his true purpose is completely shielded from the subject's awareness. Nonetheless, his primary duty is to the protocol. In this respect, his body represents an extension of the clinical gaze of the investigator. While he never entirely gives up his duty to protect the health of the subject, some of the gestures he makes that would ordinarily fit within a treatment plan are not intended to help Nikita heal, but to test her body's endurance, stamina, and organic functioning. When he draws blood, it is not so samples may be sent to the lab to aid in the diagnosis of illness. Instead, he draws blood with the aims of the protocol in mind.

Given this description of how this transformation of the lived healthy body to the body-as-object is made possible, it remains to be seen how the subject experiences the body-as-object. It should be noted that the lived body is not entirely annihilated during this transformation. In fact, to speak of it as a transformation suggests that the change is linear and irreversible. This is not the case. Instead, the lived body is obscured by the experience of the body-as-object but does not disappear entirely. If it did, there would be no subjective experience of the tension between the lived body and the body-as-object that could be reported to the investigator. As Nikita's story shows, this tension is apparent and its description is revelatory in its implications for the enterprise of clinical research.

In the mode of reflection where the body is revealed as a material entity separate from the self, the disruption of this continuity threatens the integrity of the person. Suffering is often said to be a result of the fragmentation of the self.[26] In this sense, the objectification of the body and the bifurcation of the body-subject are traumatic events. As mentioned above, the body-as-object is first experienced "in the gaze of the Other."[27] This bifurcated apprehension of the body-as-object and subject simultaneously leads to an alienation of the lived experience of the body. As objectified by the gaze of the Other, it becomes a thing "outside my subjectivity."[28] There is also a felt sense of loss in the totality of the body schema. Within the regime of the body-as-object, the experience of being an object that is observed, measured, probed, and prodded for data-gathering purposes is an experience of the uncanny.

In general, the essence of the experience of the uncanny is the "recognition in a given object or situation of something strangely familiar"[29] but not completely familiar. The experience is one of disruption of the lifeworld where the everyday seems disjointed. During the transformation of the lived body to the body-as-object, feelings of uncanniness arise in response to a failure to surpass the body. Bodily resistance is encountered where none is expected. In these moments of recognition of the materiality of the body, it is clear that "something which ought to have remained hidden … has come to light."[30] The hidden presence of the body reveals itself in the subject's realization that she is her body but this body that she is unrecognizable because it has been penetrated by

[26] Eric J. Cassell, "The Nature of Suffering and the Goals of Medicine," *New England Journal of Medicine* 306, no. 11 (March 1982): 639-645.

[27] Toombs, 58.

[28] Ibid., 59.

[29] Stephen Burwood, "The Apparent Truth of Dualism and the Uncanny Body," *Phenomenology and the Cognitive Sciences* 7, no.2 (June 2008), 270.

[30] Ibid.

scientific instruments or has been placed in an unfamiliar environment. This failure to integrate the lived experience of the body with the environment and the instrumental relations that constitute it results in a more disturbing realization that she is her body but this body that she is is an object for others. It is in this relationship of knowing and being that objectification of the body as a physiological organism takes root.

As the hidden presence of the body as a biological object surfaces, subjects realize that it “includes events, processes and structures over which [they] have no control and of which [they] have no awareness."[31] This sense of a body that is not only unrecognizable, but also essentially uncontrollable and incomprehensible can be disarming and frightening. In this regime of power/knowledge, whoever controls the production of biological knowledge has power over the black box that is the body-as-object. The lived experience of the uncanny body is a life lived in symbiosis with an “alien presence” that controls the self and has its own moods.[32] In this sense, the moods of the body-as-object may be manipulated by those who control the mechanical knowledge necessary to alter these moods to suit their purposes. Alienation comes from a sense of being-in-the-world that recognizes the self as belonging to a world that also belongs to the Other. Thus, there is a sense of "mineness" and "Otherness" about the world. Fredrik Svenaeus calls this ontology, "unhomelike being-in-the-world."[33] Seeing the body-as-object or as uncanny limits the possibilities of the lived body, thus making surpassing the body impossible. Failure to surpass the body in one’s intentional interactions with the world renders it much less homelike.

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[31] Toombs, 61.

[32] Ibid.

[33] Fredrik Svenaeus, "The Phenomenology of Health and Illness," in *Handbook of Phenomenology and Medicine*, ed. S. Kay Toombs (Dordrecht, Netherlands: Kluwer Academic Publishers, 2001): 101.

RECONSTITUTING THE BODY AS A SCIENTIFIC OBJECT

As Nikita was placed into bed for the first night, she began immediately to reflect on the physiological reactions that her body was experiencing. She struggled to localize the sensations as her blood volume shifted in response to the alteration in her body's sense of gravity. She could feel her central nervous system struggling to stabilize itself as her entire body rebelled against her new positional relationship with the world. To her, it felt as if her body was at war with itself. Sensations she had never felt before flooded her body as it revealed itself as an uncanny presence. Instead of the easy relationship of active engagement that she felt during her life outside of the lab, Nikita began to see her body as an encumbrance. Her story does not end here, however, as it forms a narrative thread that links each of the following chapters. Nikita will reappear in the final chapter in conversation with the primary investigator in charge of the clinical study who will attempt to address her concerns regarding her bodily intentionality and body schema.

Nikita's account provides a narrative basis for discussions of how the transformation of the body-as-object into the body-as-scientific-object presents a second degree of alienation, one that cuts deeper since it is not part of the everyday experience of seeing the body-as-object. As a participant in clinical research, Nikita became divorced from her lifeworld and the projects and possibilities of the clinician-investigator took precedence. In order to make this transition possible, her body was disciplined so that it was reconstituted as an ideal working object.

In his work on the disciplining of the body within the penal and military systems, Foucault explains how authority figures use their control of time and bodily gestures to discipline the bodies of those who have submitted to their authority. It was "through this

technique of subjection [that] a new object was being formed; slowly, it superseded the mechanical body—the body composed of solids and assigned movements … this new object is the natural body, the bearer of forces and the seat of duration; it is the body susceptible to specified operations, which have their order, their stages, their internal conditions, their constituent elements."[34] In order to discipline the lived body and conceptualize man as a biological object that may serve as an object of scientific study, investigators must construct a new subjectivity for human subjects. The body-as-object is the mechanical body, albeit a machine that runs silently. The body-as-scientific-object is the natural body; it is capable of being manipulated as an object of scientific inquiry. In some sense, the body that emerges as a working object of scientific inquiry is seen as both mechanical and natural. It can be imposed upon by regimes of power/knowledge. These regimes are imposed along the lines of measurement and quantification. They emerge as patterns of disciplinary practices within the clinical research enterprise that reconstitute time as objectively measurable.

Objective time is time as gauged by clocks and calendars and in the clinic is used to track changes in various physiological parameters. However, during the everyday lived experience of the body, time is lived according to the internal flow of subjective experience as it points to intentional moments within objective time. By constructing time as a measurement of objective experience and disregarding the familiar experience of time as a subjective experience in itself, investigators reconstruct the body as a working scientific object. As Foucault explains, "in becoming the target for new

[34] Michel Foucault, *Discipline and Punish: The Birth of the Prison*, trans. Alan Sheridan (New York, NY: Random House, 1975), 155.

mechanisms of power, the body is offered up to new forms of knowledge."[35] These new forms of knowledge are primary mathematical in their form and content.

The quantification of the body and bodily spaces is a key part of the process of rendering the body-as-scientific-object. Treating the body as a mathematical model is an extension of the mechanical reductionism often associated with René Descartes. By normalizing the unruly lived body, investigators hope to gain a sort of epistemic credibility that would not survive scrutiny unless its accuracy could be mathematically proven. By treating the body of the subject as a statistic, investigators are able to achieve the kind of numerical proof that will become rhetorically persuasive. In Drew Leder's view, "by purging the body of spontaneity, willfulness, and occult desires, Cartesian dualism did away with all properties which might have impeded the mathematical-causal analysis of physical functioning."[36] Lived experience in general is epiphenomenal to investigators. It conceals what needs to be extracted, discovered, and tested using the rigors of mathematics.

As a scientific object, the body is transformed from the lived body to the anonymous and fungible physiological body. Bodies become paradigms of the scientific knowledge embedded in working objects. Subjects' bodies become "exemplar[s] of *the* human body," not a particular person's body.[37] Placed securely within the regimen of the protocol, my body "escapes me toward a being-a-tool-among-tools … and this is accompanied by an alienating destruction and a concrete collapse of *my* world which

[35] Ibid..
[36] Leder, "Medicine and Paradigms of Embodiment," 30.
[37] Toombs, 77.

flows toward the Other and which the Other will reapprehend in *his* world."[38] Being heard by the stethoscope and being seen by the MRI machine places my body as a tool for others. The spaces around my body flow away from me and towards the investigator, and I am aware of existing for the Other.

If the natural attitude is the unreflective mode of being in the world in which the body is experienced as lived, then the scientific objectification of the body occurs in the naturalistic attitude. Within this attitude, the body is not only thematized as object, its essence is revealed to be a scientific means to scientific ends.[39] It is the quintessential body-for-others. To be thematized in such a way is to be reduced to loosely arranged series of quantifiable phenomena. The lifeworld of the human subject is no longer simply given but demarcated and given a single meaning-structure; the person is meaningless and the body is meaningful only insofar as it yields useful data. In this mode of reflection the body is "transformed from lived body to anatomical body and, as such it assumes the guise of a corpse."[40] Since the body still lives, it is, of course, only metaphorically seen and treated as a corpse (as opposed to being seen and treated as lived body).

As has been widely acknowledged, modern medicine is based on the "dead, or inanimate, body."[41] Medical research depends on the availability of living physiological specimens that may be reduced not just to corpses, but to data points that are extracted from the measurements taken from these bodies as they perform for the investigator. Metaphorically speaking, corpses are the ultimate examples of bodies that are disciplined,

[38] Sartre, 328.
[39] Toombs, 77.
[40] Ibid., 78.
[41] Leder, 17. See also Foucault, *The Birth of the Clinic*; Drew Leder, *The Absent Body* (Chicago, IL: University of Chicago Press, 1990); and Jeffery Bishop, *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying* (Notre Dame, IN: University of Notre Dame Press, 2011).

controlled, and transitory. As mere *res extensa*, the body of the subject as scientific object adopts the passive receptivity of the corpse. Seen only as anatomico-physiological objects, bodies cannot and do not "represent the synthetic unity of a particular life, the embodiment of a unique individual."[42] As a scientific object, the body is further reduced to systems, organs, tissues, cells, and proteins. Life is what covers over the phenomena investigators wish to observe. Investigators seem to think that they need a "*dead* universe, devoid of subjectivity and intention."[43] As I will show in the remainder of this dissertation, this assumption is false. Not only is it false, but it has also led to both violations of human dignity and substandard science.

In sum, objectification occurs when investigators conceptualize subjects as merely physical entities that are indistinguishable from other material entities in the world. In a mode of reflection upon their situation, subjects then internalize this objectification as a result of how they are treated while participating in clinical trials. On Burwood's view, this internalization "results in an existential conflict in which one's very sense of self is brought into question and one's autonomy and freedom to formulate projects and to engage freely with others may be severely curtailed."[44] While one might rightly suggest that the freedom to engage with others is not normally severely curtailed as a result of participating in medical research, as I will show in Chapter 2, there are historical episodes where this was the result.

[42] Toombs, 78.
[43] Leder, 20
[44] Burwood, 267.

Chapter 2: Inscribing the Other as Scientific Object

In this chapter, I will describe a series of historical episodes that reified the various mechanical, industrial, and agricultural metaphors outlined below. These metaphors craft a vision of the human body that inscribes it within the discourse of medical research as a mere scientific object to be studied. They also serve to structure the moral and existential perspectives from which investigators have operated since the early twentieth century. The language of medical research is ripe with metaphors that demean and dehumanize persons by reducing them first to mere mechanical bodies and then to objects that are valuable only insofar as they are useful to medical investigators. In Lori Andrews and Dorothy Nelkin's view, "such a language reflects a set of cultural assumptions about the body; that it can be understood in terms of its units, and that these units can be pulled from their context, isolated, and abstracted from real people who live in a particular time, at an actual location, in a given society."[1] Throughout this chapter I will demonstrate the existential and moral effects of treating persons as objects. In the following chapter I will show how alternative metaphors might be used that can capture elements of humanity that are neglected by the current language of medical research. Before I discuss the metaphors that constitute the rhetoric of reductionism, it will be helpful to consider how persons are objectified under the clinical gaze by considering those elements of self that are undermined by these metaphors.

In her essay on the objectification of women, Martha Nussbaum cites instrumentality, denial of autonomy, inertness, fungibility, violability, ownership, and

[1] Lori Andrews and Dorothy Nelkin. *Body Bazaar: The Market for Human Tissue in the Biotechnology Age* (New York, NY: Crown Publishers, 2001), 6.

denial of subjectivity as components of objectification.[2] If investigators are following the notion of respect for persons explicated in the Belmont Report, they are likely not denying the autonomy of human subjects. Furthermore, it is not my intention to focus on autonomy as a feature of respect for persons or of objectification since part of my argument is that this feature has already been given sufficient attention. However, the other six elements are all present in some form in the rhetoric of reductionism that dominates the research enterprise and so deserve some consideration.

In the schema of scientific objectification, the concept of instrumentality is integral to determining the moral status of bodies and persons. To use the bodies of other persons only for one's own ends is to treat them as instruments of another's will, while using one's own body for one's own ends is in itself morally neutral. As Nussbaum argues, instrumentality does not "entail lack of consideration for feelings and subjectivity."[3] However, the meaning given to the term as it is used in the rhetoric of reductionism seems to preclude such considerations. In the context of the scientific inscription of the body as a working object, the instrumentality of the body becomes an impediment to the freedom of body-subjects, since "feelings and subjectivity" are of no concern to some investigators. Instrumentality in this context serves to ground other aspects of the objectification of the body-subject in human subjects research.

While both persons and bodies are rarely inert, participation in medical research requires that they become passive recipients of the tools that actualize the active will of the research team. Although the informed-consent process is often successful in recognizing the agency of the potential human subject, this agency is still constrained by

[2] Martha C. Nussbaum, "Objectification," *Philosophy and Public Affairs* 24, no. 4 (Autumn 1995): 257.

[3] Ibid., 260.

the boundaries of the clinical trial itself. Human subjects are expected to restrict their activities to those that do not violate the parameters of the trial. Thus, their agency is constrained by the choices permitted within this realm. The clinical gaze is responsible for imposing this regime of docility. In Foucault's view, docility "joins the analysable body to the manipulable body."[4] To be placed within a regime of scientific instrumentality is to be seen and treated as merely the site of knowledge production. To this end, subjects' bodies become the site of the production of a new kind of subjectivity, a regime of power/knowledge whose aim is to discipline the unruly body in order to know it as a certain kind of working object. This relationship of power/knowledge to docility will be explored further in this chapter, as will the next topic for consideration under the schema of scientific objectification: fungibility.

The fungibility of bodies in clinical research makes the commodification of the body possible. Although I will explore this connection in greater detail in a later chapter, it is worth noting here since fungibility is a dimension of instrumentality. The interchangeability and anonymity of bodies within the clinical trial make it easier for investigators to deny subjects' subjectivity and individual intrinsic value. If a body is not tied to a person but is just one object among others, it becomes useful only in the roles that this set of objects plays. It becomes a tool to be used at the whim of those who have power over it. Epistemic necessity along with fungibility makes the violation of bodily boundaries for scientific ends thinkable.

The permeability of bodily integrity is at the heart of medical research using human subjects. Without subjects' consent to the probing of the intimate recesses of the body, investigators would have no material for their extrapolations and no data on which

[4] Foucault, *Discipline and Punish*, 136.

to base their conclusions. Yet, there is something fundamentally troubling about allowing certain bodies to be violated, even with the consent of the subject. For example, the scientific objectification of the body only reaches a certain segment of the population because only certain populations are enrolled in clinical trials. Some bodies that are viewed as unproductive are, through their penetration by the clinical gaze, made to become useful to the body politic.[5] Violability and permeability become a problem of social justice when only certain kinds of bodies are selected to be violated. However, the more fundamental problem of distorted moral vision occurs when investigators see the body merely as an object whose boundaries are permeable and may be violated for the health of other bodies or for the body politic in general. In their role as seekers of body knowledge, investigators may be persuaded by the rhetoric of reductionism that human subjects have conceded temporary ownership rights to their bodies. Adopting this view of the body as a commodity creates the illusion that its boundaries may be traversed at will once consent has been given.

Nussbaum argues that commodification is part of the relation of ownership that objectification of the other creates.[6] It is clear that when subjects give their consent to participate in clinical research they are not giving away ownership of their bodies. However, they are acquiescing to the commodification of their bodies and body parts. Commodification of the body creates tension between the original owner of the commodity and the end use of that commodity, as the Henrietta Lacks case

[5] See Goodman, et al., *Useful Bodies: Humans in the Service of Medical Science in the Twentieth Century*.

[6] Nussbaum, 257.

demonstrates.[7] This tension may be further understood as a power dynamic that develops between the investigator and the subject. With his advanced scientific training and skills in clinical medicine, the investigator holds an advantage over the subject in terms of how the research relationship is managed. As I have suggested earlier, following Foucault, these relations of power cannot be established without the production of a discourse of which the rhetoric of reductionism is a part.[8] In fact, it is the investigator's power over the body of the subject that makes "physiological, organic knowledge of it" a possibility.[9] This power is demonstrated by the rigors of the clinical-trial regimen, the prescription of a scientifically constructed diet, the monitoring of physical activity, and the temporary confinement of the body within the apparatus of the enterprise. The investigators' power over the body transforms it from the lived body to the body-as-object. It becomes the body "manipulated by authority, rather than imbued with animal spirits."[10] In order to subjugate the body of the human subject fully, investigators must deny the subjectivity of the subject.

Although some commentators have replaced the term "human subject" with the term "human participant," as my remarks on docility have suggested, there is really a very limited space in which subjectivity is welcomed within the research enterprise. It is the investigator's power over the body that deprives body-subjects a shared space in which to construct meaning. Eliminating subjectivity from the epistemic space of the clinical-research enterprise creates moral lacunae between the investigator and the

[7] See Rebecca Skloot, *The Immortal Life of Henrietta Lacks* (New York, NY: Crown Publishers, 2010).

[8] Michel Foucault, *Power/Knowledge - Selected Interviews and Other Writings 1972-1977*, ed. Colin Gordon (Brighton, UK: Harvester Press, 1980), 93.

[9] Foucault, *Power/Knowledge*, 59.

[10] Foucault, *Discipline and Punish*, 155.

subject. These lacunae can be filled in a therapeutic relationship, but it is much more difficult to cross these gaps in the investigator-subject relationship. Patients and physicians can construct meaning together based on a shared concern for the health of the body and the lifeworld of the patient. The common ground that can help investigators and subjects discover the meaning of the research enterprise is not so readily apparent. In fact, there are significant epistemic barriers that obscure these foundations, as I have noted earlier in my remarks on fungibility and instrumentality. In Robert Helms's view, "they don't care about what you are thinking and they don't want to be talked about, they just want your body to do something."[11] Other subjects report consciously dissociating their minds from what is happening to their bodies by thinking about how compensation will be used.[12] Nonetheless, the denial of the content of subjective thought and experience within current scientific discourse does not mean that there is no place for this content, nor does it mean that demarcating spaces within the discourse for subjective experience is inappropriate. Furthermore, recognition of the subjective experience of the human subject is a necessary part of the embodied view of respect, but it alone is not sufficient.

THE RISE OF THE BIOMECHANICAL REDUCTIONISM OF BODIES

Readers who are familiar with the language bioethicists use to criticize what they perceive as the dehumanizing nature of medicine and medical research will recognize the metaphor of the body as machine as being integral to that critique. For bioethicists following in the footsteps of psychiatrist George Engel, the reductionistic view of the lived body as a mere machine alienates patients from their essential nature as embedded

[11] Abadie, 48.
[12] Ibid., 47.

and embodied persons.[13] The mechanical metaphor in its modern form is based on the belief that "every biological system can be understood in terms of the laws that govern chemical or physical processes apart from biological systems."[14] While it may be reductive and dehumanizing, this metaphor has its practical uses. Understanding some features of the body along mechanical lines may be helpful in explaining how the body functions and in testing hypotheses about its functionality. The metaphor of the body's cells as machines that is often taught in high school biology—for example, that the mitochondria is the powerhouse of the cell—is a helpful way of explaining complex concepts to the wandering mind of a secondary school student. This metaphor may also be carried through to the level of organs—for example, the heart is often compared to a pump and the brain to a computer. Using these analogies, investigators and science students have found it easy to work out a rudimentary understanding of the body. However, the metaphor may be stretched too far and may lead to persons being treated as mere machines. When bodies are seen as mere machines, they may be treated as morally neutral objects since they "possess neither nobility nor inferiority."[15] This way of treating humans is inexcusable as it denies the inherent value and nobility of the person as well as the body. Furthermore, features of human life and the human body that are not explicable in mechanical terms do not fit within this metaphor and so are disvalued. In addition, seeing disease as an entity and not as a process encourages investigators to see research

[13] George L. Engel "The Need for a New Medical Model: A Challenge for Biomedicine," *Science* 196, no. 4286 (April 8, 1977): 129–136.

[14] Eric J. Cassell, "The Body of the Future," in *The Body in Medical Thought and Practice*, ed. Drew Leder (Dordrecht, Netherlands: Kluwer Academic Publishers, 1992), 237.

[15] Jonathan Sawday, *The Body Emblazoned: Dissection and the Human Body in Renaissance Culture* (New York, NY: Routledge, 1995), 130.

subjects as objects which may contain a disease or serve as a disease model.[16] The human body then becomes nothing more than a vessel from which one may extract knowledge about disease entities.

Within mainstream bioethics, the history of the mechanical metaphor normally begins with the imagery adopted by René Descartes to describe the human body. In the *Discourse on Method*, Descartes compares the human body to automatons "or moving machines fabricated by human industry." [17] Compared to the human body, these simple machines are not nearly as well-designed, yet they are powered by the same mechanical laws. Descartes argues that "persons will look upon this body as a machine made by the hands of God, which is incomparably better arranged, and adequate to movements more admirable than is any machine of human invention."[18] Of course, Descartes was not alone in his use of the mechanical metaphor. William Harvey used the idea of the heart as a pump to help him solve what Richard Shryock called "a problem in mechanics."[19] Harvey's work on the circulation of the blood as a mechanical problem was an ideological compromise between the vitalism of the medieval age and the growing popularity of a view of the "animal body as [either] a machine or as a chemical

[16] Paul Hodgkin, "Medicine is War and Other Medical Metaphors," *BMJ: Clinical Research Edition* 291, no 6511 (December 21-28):1820. Hodgkin is referring to patients in his discussion, but the same idea is easily transferrable to subjects who are not patients.

[17] René Descartes, *Discourse On The Method Of Rightly Conducting The Reason And Seeking Truth In The Sciences* Part V. http://www.gutenberg.org/files/59/59-h/59-h.htm.

[18] Ibid. Note that Descartes's machine body was not merely a functional replica of the automatons built by human hands, but a beautiful marvel that surpassed any machine that man could hope to design. The machine body also may be seen through an aesthetic lens and not only through the lens of functionality and the search for mechanical laws.

[19] Richard H. Shryock, *American Medical Research, Past and Present* (New York: Commonwealth Fund, 1947), 14.

complex."[20] This idea would continue to be refined and expanded from the seventeenth century onwards.

The modern mechanistic view of the body was inherited from a confluence of scientific and broader cultural paradigms. As psychologist Alphonse Chapanis noted, "Newton's mechanics brought forth models of man which treated him simply as a machine made up of levers and similar linkages. Watt's steam engine and the development of thermodynamics produced models of man which viewed him as nothing but a complicated heat engine. When servomechanisms mushroomed during World War Two we heard that man is nothing but a servosystem."[21] Thus, models from engineering, physics, and early forms of artificial intelligence were added to the Cartesian model of the body described above. During the early twentieth century, ideas from architecture and the industrialization of the labor force were also added to this complex bouillabaisse. One such example is the fascinating summary of a human body reduced to its mechanical properties offered by the architect Buckminster Fuller:

> A self-balancing, 28-jointed adaptor-based biped; an electro-chemical reduction plant, integral with segregated stowages of special energy extracts in storage batteries, for subsequent actuation of thousands of hydraulic and pneumatic pumps, with motors attached; 62,000 miles of capillaries, millions of warning signals, railroad, and conveyor systems; crushers and cranes … and a universally distributed telephone systems needing no service for 70 years if well managed; the whole extraordinary complex mechanism guided with exquisite precision from a turret in which are located telescopic and microscopic self-registering and recording range finders, a spectroscope, et cetera.[22]

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[20] Ibid.

[21] Alphonse Chapanis. "Men, Machines and Models" *American Psychologist* 16, no.3 (March 1961): 113.

[22] Buckminster Fuller (1938), quoted in Samuel Osherson and Lorna Amara Singham, "The Machine Metaphor in Medicine," in *Social Contexts of Health, Illness, and Patient Care*, ed. E.G. Mishler (Cambridge, UK: Cambridge University Press, 1981), 220.

Although incredibly reductive, this imaginative description includes a range and amalgamation of industrial and mechanical metaphors that accurately capture the human body as a highly complex machine. It is this more sophisticated view that most accurately reflects the biomedical (or biomechanical) model that medicine has adopted.

The emergence of biomechanical reductionism in medicine is due to a confluence of factors, many of which are related to the unquestioning acceptance of the Cartesian model described above. As with the industrialization of medicine, which will be discussed later in this chapter, the professionalization of medicine through the Flexner Report was instrumental in the perpetuation of this metaphor. Abraham Flexner's report on medical education in America during the early twentieth century was integral to instantiating reductionism in medicine through the attention he paid to the idea of bodies as "systems unrelated to other systems of the body."[23] His ideal model for the American medical school was based on the Germanic model as imitated by Johns Hopkins University. William Welch, the architect of the medical school at Johns Hopkins, insisted that future physicians be trained in physiology, bacteriology, and pathology. Education in the methods of laboratory medicine outweighed the emphasis placed on public health and patient care at Johns Hopkins. Following this model, the American medical system was driven by the anatomico-pathological understanding of man as a biological object that could be invaded by foreign disease entities. This biomechanical paradigm supplanted the idea of persons as empirico-transcendental, socially embedded beings whose experience of illness may also derive from social determinants of health. Biomechanical explanations of human functioning were also used to explain social facts like industrialization and the politics of the body as a source of labor.

[23] Ibid., 228.

During the Progressive Era of the 1920s, Western society experienced the corporatization of labor within a hierarchy controlled by the professions and the movement of capital. From these economic and industrial developments, the metaphor of society as a machine composed of individual machines emerged as a way to address the social transformation of American society from a predominantly agrarian to a predominantly industrial economic base.[24] When this machine started to break down under the stress of the Depression and the outbreak of World War Two, social problems were medicalized.[25] This medicalization bred interest in developing technological solutions. The mechanical metaphor fits neatly into this schema. In Samuel Osherson and Lorna Singham's view, "machine models of the body and mechanistic notions of science are particularly amenable to the development of technological rather than social solutions to problems … they provide discrete, testable, certifiable bodies of knowledge that can be defined as the purview of one professional class."[26] Indeed, the confluence of mechanization in industry, the corporatization of labor, and the overhaul of medical education promoted the professionalization of medicine and spurred the industrialization of medical research.

Placed against this background, the mechanical metaphor seems to be deeply engrained in the paradigm of modern medical research as a scientific enterprise as well as the psyche of the investigator. Resistance to this metaphor is often drawn from sources outside of medicine. Yet, there are a few voices from within the profession that resist the power of this metaphor. Eric Cassell argues that "when the body is viewed as a

[24] Ibid.

[25] Ibid., 231. See also Anne E. Harrington, *The Cure Within: A History of Mind-Body Medicine* (New York, NY: W.W. Norton, 2008).

[26] Osherson and Singham, 231.

mechanism, the word *purpose* is supplanted by the word *function*."[27] What is of interest to investigators is how the body functions under duress, not the purpose of the body. Cassell argues that both bodies and body parts also have purposes. Cassell's argument rests on the integration of the whole person as a being that has interests, values, and beliefs about the world. These features of bodily schema and intentionality cannot be separated from the body parts that make action in the world possible. As instruments of the will of the body, body parts have purposes that cannot be explained by appeals to their function as organic mechanisms or structures. Cassell's argument warns against the kind of "total alienation of the human spirit from the scientific and rational world" that is an inevitable product of the unreflective and imprudent use of this metaphor by investigators.[28]

Placed within the context of industrialization, the metaphor of the body as machine takes on additional characteristics. Instead of being viewed merely as a self-sustaining mechanism composed of organic structures, the machine is brought to life by extending its inner workings to an external world that is equally explicable in mechanical terms. Organs and organ systems are seen not just as internally necessary for animating the machine body, but as integral parts of a mechanized world. Human bodies became the mechanical means for reaching social goals of productivity and efficiency through the refinement of the machine body—that is, through the maintenance of the health of industrial workers. Thomas Schlich points to the rechristening of hospitals as "health factories" during the early part of the twentieth century as an indication of this way of

[27] Cassell, 240.

[28] Soma Hewa and Robert W. Hetherington, "Specialists Without Spirit: Limitations of the Mechanistic Biomechanical Model," *Theoretical Medicine* 16, no.2 (1995): 131.

seeing and naming.[29] In this sense, the methodology of engineering was applied to both the body per se and the training of the American labor force. The ideological consequences of the merging of these methodologies led in part to the development of the metaphorical understanding of the body as a factory of knowledge. The machine body thus provides the foundational image from which the metaphor of the body as a factory of knowledge is derived.

THE INDUSTRIALIZATION OF BODIES: AN HISTORICAL OVERVIEW

Institutional pressures both from inside and outside of medical science, including those described above, led investigators to treat subjects' bodies as potential factories of knowledge. This metaphor has its roots in the industrialization of the medico-scientific enterprise during the twentieth century. While not explicitly used by investigators, it is apparent from the historical evidence that this metaphor appropriately captures the way in which persons and bodies were seen and treated. In order for factories to function, they must contain workers. In the case of this metaphor, these workers were the mechanical features of the human body alluded to earlier in the description of the mechanical metaphor. This "industrial metaphor" serves to organize the mechanical metaphor but requires the assumptions of the mechanical metaphor to become operational. While the mechanical metaphor simply reduces the body to a machine, the industrial metaphor multiplies the machines and switches the focus from the internal workings of the body to the data that bodies produce. Though a single human body can be considered a factory that produces knowledge in the form of quantifiable data about its own physiological

[29] Thomas Schlich, "The Perfect Machine: Lorenz Bahler's Rationalized Fracture Treatment in World War I," *Isis* 100, no.4 (December 2009): 760.

functioning under normal and experimental conditions, for this metaphor to accurately capture the spirit of industrialization and mass production that permeates the enterprise, it must be considered as a metaphor that describes multiple bodies. Taken together, human bodies produce data points that can be measured by other machines, thus generating a product that itself may continue to be processed and used to intervene in other bodies. As a rhetorical device, use of this metaphor to justify the need for and orchestrate the use of certain research methodologies has both epistemic and moral implications.

As the epistemic norms internal to medical science changed with the progression from animal to human models of disease processes and the rise of controlled clinical trials in the late nineteenth and early twentieth centuries, the need for human bodies grew exponentially. Before World War Two, research was not industrialized. Instead, clinical studies were predominantly modest affairs involving relatively small sample sizes and a few committed investigators working with limited budgets and facilities. In the United States, frontier physicians like J. Marion Sims and William Beaumont worked alone or in small groups in their communities with a few patients.[30]

As the twentieth century progressed, these small trials produced successful interventions, like streptomycin for tuberculosis, penicillin, and other so-called magic bullets. Investigators across the globe began to search for the next magic bullet and used these successes to persuade governments and private industries to sponsor larger clinical trials. There were several important moral and epistemic features of medical research that

[30] David Rothman, *Strangers at the Bedside: A History of How Law and Ethics Transformed Medical Decision-Making*. (New York: Basic Books, 1991), 21. See also Susan Lederer, *Subjected to Science: Human Experimentation in America Before the Second World War* (Baltimore, MD: Johns Hopkins University Press, 1995); Deborah Kuhn McGregor, *Sexual Surgery and the Origins of Gynecology: J. Marion Sims, His Hospital, and His Patients*, (New York: Garland Pub., 1990); and Ronald L. Numbers, "William Beaumont and the Ethics of Human Experimentation," *J History Biology* 12, no1 (Spring 1979): 113-135.

developed out of the success of these smaller trials. The demand for higher standards of evidence led to a corresponding demand for more bodies to participate in clinical trials. In turn, this epistemic necessity led to the moral quandary of where to find enough healthy bodies for a clinical-trial industry that was expanding exponentially.

During this time period, the credibility of an experiment normally relied on the testimony of qualified experts, not the numerical methods of quantification and statistical analysis. As larger cooperative studies became possible in the early twentieth century, the production of generalizable knowledge required that certain statistical standards of evidence be met. In terms of the epistemic norms of medical science, the influence of public-health researchers and statisticians filled the need for investigators to develop standards of evidence that could move beyond those used during the age of smaller historical trials.

Prior to World War Two, there were several factors that led to the industrialization of bodies. One of the major factors was the development, refinement, and expansion of the experimental methodology that powers medical research. However, the impetus for the interest in developing more reliable methodologies also has its roots in the professionalization of medicine, which was made possible by developments in the late nineteenth century, especially the bacteriological revolution.

With the isolation of bacteria that caused tuberculosis and other diseases, Robert Koch provided the empirical evidence and the scientific methodology necessary for establishing the germ theory of disease. By tracing bodily pathology to specific disease entities, Koch and others helped to generate a new model for understanding health and illness. This bacteriological revolution stimulated a call for living bodies that could

satisfy the evidentiary standards set by Koch's postulates. Healthy bodies were necessary as controls, but bodies exhibiting pathologies thought to be related to the bacteria in question were absolutely essential. The latter served as vessels for the extraction of the germ but could not be used to confirm the presence of a cultured version of the germ. For this purpose, healthy bodies were necessary. Now that physicians could offer treatments based on specific disease entities that could be isolated and studied, a whole new range of therapeutic advances became possible. Where once therapeutic nihilism and infighting among the various medical schools of thought threatened the profession, the bacteriological revolution provided allopathic practitioners with empirical evidence that their methods were superior.

Even before Koch's discovery of the Mycobacterium *tuberculosis*, pathologist and physician Elisha Bartlett argued that the "certainty of result will be in proportion to the fixed and uniform character of the compared facts and to the greatness of their numbers."[31] Although observational studies were still the norm, early nineteenth century physicians began to emphasize the "need for a careful statistical approach in the evaluation of remedies," an idea that was already popular in Europe, particularly France.[32] In the arguments for the use of large numbers for the purpose of statistical certainty one finds the origin of the industrial metaphor as an expression of the need for human clinical material. Seen in this manner, the lived body becomes a statistical body, a mathematical model to be used in a statistical calculus. The statistical body is the industrialized body, the body as a factory that produces knowledge by producing numbers. This statistical calculus would later be supported by a moral calculus via the

[31] J.P. Bull, "The Historical Development of Clinical Therapeutic Trials," *Journal of Chronic Diseases* 10, no.3 (September 1959): 232.

[32] Ibid., 231.

utilitarianism of Jeremy Bentham and J. S. Mill (both were products of the nineteenth century). The entanglement of the statistical imperative with the utilitarian calculus would have to wait, as physicians like Barlett, though they were attuned to the "danger of losing sight of the individual in the statistical group," were only concerned at the time with how individual cases affect the composition of the group, not in their intrinsic value.[33]

Although biostatistics would not be added to the list until later in the century, biochemistry, bacteriology, pathology, and physiology became the focus of the American medical education system following Flexner's groundbreaking report in 1910.[34] In keeping with the spirit of Flexner's reform of medical schools, clinical investigators realized that professionalization of medical research as a field would demand that physicians move beyond basing their beliefs about a therapy by vicariously considering the risks and benefits as though they were the patient. Anecdotal and observational evidence were no longer sufficient in an age when pursuit of the means for eradicating infectious diseases was such a high priority. In the wake of the Spanish Flu pandemic of 1918, investigators began to search for a methodology that would allow them to apply the new germ theory of disease to a large population. Furthermore, World War I "raised new problems of large scale prophylaxis and treatment in medicine and surgery."[35] In 1936, W. D. Sutliff introduced a paper on the latest experimental methods with the hope that his report "will aid in defining standards of achievement for those who advocate new cures,

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[33] Ibid., 232.

[34] Abraham Flexner, *Medical Education in the United States and Canada Bulletin Number Four (The Flexner Report)*, The Carnegie Foundation for the Advancement of Teaching. http://www.carnegiefoundation.org/publications/medical-education-united-states-and-canada-bulletin-number-four-flexner-report-0.

[35] Bull, 231.

and also contribute to a better reasoned attitude by the profession when they are confronted with reports of therapeutic success."[36] He goes on to contrast a purely observational study of quinine with two others that introduced control groups and a basic statistical analysis. Though he seems to question the efficacy of the use of statistics in medical research, Sutliff remains open to the idea that these methods may prove more effective when simple observational methods are not sufficient. As clinical trials became more complex and the small samples normally used in observational studies were proven to be no longer sufficient, investigators began to argue for larger sample sizes. In other words, they needed more bodies to make the factory run.

Organizing demands for stricter standards of evidence required a metaphor that captured the demand for accruing usable bodies on a massive scale. Accordingly, the metaphor of bodies as factories suggests that in order to be useful for medical research, bodies have to be gathered together en masse. A single body produces knowledge, but it is not generalizable. Thus, each body must be broken down into data points that are compiled to produce objective knowledge--either about the body itself or the intervention being tested.

This metaphor is particularly apt when used to describe how the bodies of institutionalized individuals were conceptualized and treated by investigators during the mid to late twentieth century. By *institutionalized* I mean not only prisoners, but soldiers as well. For soldiers who were conscripted following World War Two the military used the disciplinary tools of other state-run institutions. For example, enlistment and basic training were processes that were defined by the aims of the enterprise. The basic aim of

[36] W.D. Sutliff, "Adequate Tests of Curative Therapy in Man," *Annals of Internal Medicine* 10, no.1 (July 1936): 89.

both processes is to discipline the bodies of new recruits by breaking them down and mold them into fighting machines. The military itself was a kind of machine in that it was "a hierarchically organized large enterprise that required efficient systematization and perfect coordination to function properly."[37] Soldiers' bodies were already suitable sites for the production of scientific knowledge, as they were by definition healthy enough to serve the body politic. Most were young and fit. They were also all vulnerable in the sense that their service to their country placed limits on their personal freedom. Furthermore, they were already disciplined by the military system to obey orders without question, which made them paradigms of the docile body.[38]

Discourses of productivity supported and made possible the industrialization of subjects' bodies from the early twentieth century to the postwar period, especially as regards the use of soldiers, prisoners, and other vulnerable populations. By seeing soldiers' bodies as ultimately valuable only for their instrumental value in pursuing social goods, investigators tapped into the rhetoric of productivity that dominated the social thought of wartime America. This conceptualization of the body as a force of production enables it to be "invested with relations of power and domination."[39] Only bodies that have the potential for use are worth the investment of resources and discursive strategies necessary to bring them under control. In his commentary on the "heroes of the laboratory" exposed by Henry Beecher's article, which described the ethical and scientific violations of some twentieth-century investigators, David Rothman noted that "[i]t is no coincidence that this cohort of investigators took as their research subjects

[37] Schlich, 763.
[38] Foucault, *Discipline and Punish*, 135.
[39] Foucault, *Power/Knowledge*, 26.

persons who were in one sense or another devalued or marginalized."[40] These investigators were persuaded that bodies should be seen as forces of productivity, of untapped labor that should be used to serve the war effort by testing cures for diseases that affected soldiers. These investigators were caught up in the mythology of the war machine and the magic bullet, which continued to dominate the medico-scientific zeitgeist of the Cold War period. Of course, in order to produce magic bullets, one needs munitions factories.

The production of knowledge, like the production of munitions, requires a standardized and controlled environment in order to produce a uniformly reliable product. As a rhetorical device, the industrial metaphor requires the statistical normalization of the body. It also justifies the use of institutionalized persons in research, especially prisoners and soldiers, since these populations are standardized, normalized, and disciplined by the discursive and instrumental practices of their respective institutions. Prisons and barracks have the look and feel of factories. In fact, one could easily argue that there is little difference, as Foucault does, between the two.[41] Both are disciplined by a variety of power/knowledge relations. Power is dispersed equally among prisons and barracks. Prisons, barracks, and factories are managed according to how physical labor is most efficiently tapped and are configured for the efficient production of a social good through the positioning of raw materials in a confined and organized space. Time, bodily gestures, and space are already managed.[42] They serve as ready-mades for the production of knowledge.

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[40] Rothman, 80. See also Henry K Beecher, "Ethics and Clinical Research," *New England Journal of Medicine* 274, no. 24 (June 16, 1966): 1354–1360.

[41] See Foucault, *Discipline and Punish: the Birth of the Prison*.

[42] Ibid.

Through the disciplinary practices of the prison, which relied on inmates as free labor in both passive and active roles, machine bodies were essentially molding other machine bodies. The specifications for these science-ready machine bodies were outlined in the protocol, thus enabling the inmate assistants to disburse their own brand of institutional power through the instrument of scientific knowledge. In so doing, they used the template of medical research to replicate ad infinitum the properties of the ideal subject, while at the same time serving their own needs. By allowing prisoners to select other prisoners for recruitment into these trials, investigators perpetuated the standardizing power of the factory metaphor, thus removing all traces of individuality. Though there may be differences in the way that each body meets the inclusion criteria and there may be other features that these bodies possess besides their qualifications for the study, these differences are insignificant as far as the industrial metaphor is concerned. Before discussing any further how these populations were disciplined by the medical research enterprise, I must trace the origins of two corollaries of the rhetoric of reductionism, namely, the complementary discourses of statistical normativity and industrialization of the body.

As I have mentioned, in the decades leading up to World War Two, clinical investigations progressed from small, independent studies to large, cooperative studies. In order to increase the accuracy and boost the credibility of the data and conclusions drawn from large scale clinical trials, investigators began to develop modes of statistical analysis. While an in-depth discussion of these methods would be beyond the scope of this work, the arguments that were offered for increasing the size of clinical trials while maintaining their legitimacy as forms of knowledge are worth considering. These

arguments form the foundation of the rise of modern clinical trials as well as indicate why investigators thought it was necessary to recruit large numbers of subjects. Investigators, as one might expect, were primarily concerned about potential sources of error in their observations. They subscribed to the idea that the body is capable of healing itself without intervention and that this capacity for recovery without therapy might skew the results of clinical trials.[43] Thus, they began "gathering large numbers of patients to offset the effects of spontaneous recoveries."[44] Cooperative studies conducted by different hospitals had the "ability to accumulate large numbers of patients treated by a common regimen" and were therefore thought to be quite reliable.[45] However, they also introduced additional variables that could confound the results. Hospitals varied in the degree of their adherence to protocols. Some physicians were better observers and more meticulous in their record keeping than others. Most importantly, patients' bodies were also so variable that they needed to be grouped together and homogenized through the use of statistical analysis. To correct these problems, investigators at the turn of the century argued that "observations on large numbers of cases were better than observations on small numbers of cases because the variability of the disease was a relatively smaller source of error in the larger series."[46] Nonetheless, physicians were still hesitant to invite statisticians to join the research team.

As historian Harry M. Marks notes, in the early twentieth century only "a handful of leading investigators had argued for the importance of statistical methods and

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[43] Harry M. Marks, *The Progress of Experiment: Science and Therapeutic Reform in the United States, 1900-1990* (Cambridge, UK: Cambridge University Press, 1997).

[44] Marks, 53.

[45] Harry M. Marks, "Notes from Underground: The Social Organization of Therapeutic Research," in *Grand Rounds: One Hundred Years of Internal Medicine*, eds. Russell C. Maulitz and Diana E. Long (Philadelphia, PA: University of Pennsylvania Press, 1988), 309.

[46] Sutliff, 91.

knowledge in clinical research, arguing that the phenomena of disease were so variable as to require the aid of statistics."[47] For example, physicians conducting a study on lobar pneumonia in 1931-1932 in the United Kingdom for the Medical Research Council claimed that "it will be noted from what follows that a large series of cases is required in order to demonstrate fairly any beneficial action of the serum."[48] Small-scale experiments made it difficult to discover small differences, whether they were positive or negative. Large numbers would make tests to discover differences more likely to discover these small effects. Two years before the spectre of war would descend on the European continent, the editor of the *Lancet* noted the difference between how basic scientists and clinicians have approached the use of statistics in medicine, claiming that "in laboratory work, though recognition has come more slowly it is now widely realised that it is very unsafe to base conclusions on statistically inadequate data. In clinical medicine recognition is coming more slowly still; so slowly that many avoidable errors, and a sad waste of material, still hinder progress."[49]

Although the moral and existential implications of investigators needing to use large numbers of research subjects would not be fully apparent until later in the century, it is clear that along with the industrialization of the research enterprise the body as lived is obscured by the rise of the statistical body. Statistical representation breaks the subject down into phenotypic characteristics: gender, weight, height, age, health status, and so forth. Within the context of the data-gathering portion of the clinical trial and as part of the subsequent publication of the results, the lived experience of each subject is broken

[47] Marks, 136.

[48] Medical Research Council Therapeutic Trials Committee, "The Serum Treatment of Lobar Pneumonia: A Report of the Therapeutic Trials Committee of the Medical Research Council," *BMJ* 1, no.284 (February 10, 1934): 241.

[49] Editorial, "Mathematics and Medicine," *The Lancet* 229, no. 5914 (January 2, 1937): 31.

down into variables that must be controlled. Homogeneity is attempted through the disciplining of bodies while heterogeneity is discouraged through statistical normalization and representations of bodies relative to their deviation from the mean. The unruliness of bodies stands out in the minds of biostatisticians like Bradford Hill as a problem to be solved statistically. In Hill's view, "if we have been unable to equalise the group *ab initio* we must equalise them to the utmost extent by the mode of analysis."[50] Of course, he offers a scientific rationale for the move to homogenize populations, or at least to account for heterogeneity through statistics. Hill argues that "between the individuals within each group there will often be wide differences in characteristics, for instance in body-weight and state of health, but with *large* numbers we can be reasonably sure that the numbers of each type will be equally, or nearly equally, represented in both groups."[51] Thus, the methods of public health used to account for differences among individuals by aggregating and randomizing populations became part of the methodology of medical research. The epistemic, moral, and existential implications of the adoption of these methods will be traced out throughout the rest of this chapter.

Statistics as a part of the practice of medical research was actually not embedded fully in the enterprise until the 1950s. However, as shown above, the seeds of the biostatistical revolution in medicine were planted in the earlier part of the century. To summarize, investigators needed bodies in order to weed out differences that might not be attributable to the interventions being tested. This drive for more precise measurements and more accurate results than small trials would permit led to the industrialization of the enterprise and by extension the industrialization of the human body. These

[50] A. Bradford Hill, "Principles of Medical Statistics. I. The Aim of the Statistical Method; and General Summary and Conclusions," *The Lancet* 229, no. 5914 (January 2, 1937): 41.

[51] Hill, 42.

methodological arguments and the epistemic virtues they protect support the idea that investigators saw bodies as factories, even if they did not make this view explicit.

The second major factor in the industrialization of bodies was a governmental intervention known as the Federal Food, Drug, and Cosmetic Act (FFDCA) of 1938. The FFDCA established the requirement to test drugs for safety and restricted the claims that might be made about them by pharmaceutical companies upon threat of their removal from the market by the government. The Act was a political solution designed to avoid a repeat of the Elixir of Sulfanilamide episode in which more than a hundred people had died of ethyl diglycerol poisoning as a result of an unsafe drug being widely advertised and sold on the market without appropriate testing.[52] The development of the elixir began as a debate about the effectiveness of various sulfa drugs for pneumonia. Some physicians who favored sulfapyridine wanted to wait to put it on the market for "controlled evaluations on large numbers of patients."[53] Others were satisfied with allowing physicians to test it on their patients and using the evidence gathered from their observations to determine whether the drug was effective. The FFDCA signaled the beginning of a debate about evidence-based medicine that brought together academic, pharmaceutical, manufacturing, and governmental interests in regulating drugs. This requirement that drugs be tested for safety led to the need for large amounts of data to be collected. Small case histories collected by individual physicians had been the standard up to this point, but the demand for more objective and reliable data was codified and its enforcement became a matter of governmental surveillance of the pharmaceutical industry as well as the medical research enterprise.

[52] Marks, 82.
[53] Marks, 88.

While American soldiers were fighting on two major fronts and American industries were helping to supply munitions and other necessary materiel, investigators affiliated with the American military became part of the war effort in their own way. As more and more soldiers became victims of tropical diseases and other maladies associated with their deployment, generals and other policymakers became concerned that American troop strength might face reductions that would imperil the mission. As part of a general war effort that involved the mobilization of domestic industrial strength and the ramping up of productivity throughout all sectors of the economy, American physicians began working tirelessly to produce treatments for malaria, syphilis and other infectious diseases. Funding for basic and clinical research was dramatically increased, leading historian David Rothman to note, "What were once occasional, ad hoc efforts by individual practitioners now became well-coordinated, extensive, federally funded team ventures … medical experiments that once had the aim of benefitting their subjects were now frequently superseded by experiments designed to benefit others—specifically, soldiers on the battlefront."[54]

In response to the demand for vaccines and other treatments necessary for maintaining America's fighting force, President Roosevelt created the Committee on Medical Research (CMR) and Office of Scientific Research and Development in 1941. In terms of federal funding for clinical research, the CMR was a major contributor to the expansion of medical research during wartime. Organizational and disciplinary practices were put into place that could transform the lived body into the working object needed to produce data on a massive scale. The need for solutions to wartime problems was offered to the public as justification for designing protocols that were focused on results, often at

[54] Rothman, 30.

the cost of the health and well-being of subjects and the moral integrity of the research enterprise. Although it had been founded in 1937 as an organization focused on cancer research, the National Institutes of Health (NIH), bolstered by an increase in funding related to military medicine, incorporated this area of research into its mission in 1943.[55] Most of these funds went to universities that were by then "conducting health research on a scale undreamed of in the early decades of [the twentieth] century, owing in no small measure to the commitment of large public funds for the support of such investigations."[56] George Rosen argues that the growth of medical research during wartime was analogous to the rise of industry from artisans' shops or local guilds to transnational corporations.[57] This expansion often caused vulnerable populations to be lost in the shuffle, caught up in the machinery of wartime medical progress.

Part of the process of social organization, of which the industrialization of medical research is a good example, not only includes "adopt[ing] social norms and organizational controls" that would make clinical trials practicable but also requires that investigators see bodies in a certain way.[58] To some degree, these are derived from social norms in the sense that they operate according to metaphors that are socially constructed. Industrial and martial metaphors coincide at the point of the description of ends and the significance of those human machines who were used as means. As a social fact, the industrialization of bodies was interwoven with the war effort, with the need to mobilize, battle, defend, and wage war. Human bodies simply blended in with the machinery of the

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[55] Daniel M. Fox, "The Politics of the NIH Extramural Program: 1937-1950," *Journal of the History of Medicine* 42, no. 4 (October 1987): 454.

[56] George Rosen, "Patterns of Health Research in the United States, 1900-1960" *Bulletin of the History of Medicine* 39 (May-June 1965): 201.

[57] Rosen, 221.

[58] Harry M. Marks, "Notes from Underground: The Social Organization of Therapeutic Research," 298.

military-industrial complex. The medical research machine was indistinguishable from the war machine.

As the guns of World War Two fell silent amid the catastrophic damage that had nearly destroyed Europe and Japan, investigators in the United States and Great Britain turned their attention to the refinement of the experimental method of research they had developed during wartime. Their arguments for refining the use of statistical analyses of experimental data shaped the epistemic as well as the moral vision of investigators. Biostatisticians had managed to convince their physician colleagues that statistically checked information "provides unique, unequivocal answers to problems of analysis and design."[59] These problems of analysis and design were discovered in the course of defending against possible sources of bias in research. Randomization of samples, the use of controls, and the blinding of physicians and subjects became standardized in the years following World War Two. This push for statistically verified facts led investigators to see persons as mere collections of data points. Bodies were valued only in their instrumental use as potential bolsters of credibility. The more bodies one enrolled, the more credible the study, provided that each body was well disciplined and monitored.

The development of the modern randomized controlled trial (RCT) followed from the notion that "such objective measures would provide a more reliable, less biased assessment of therapeutic value, and thereby moderate practitioners' uncritical use of novel therapies."[60] As with any rhetorical practice, the key to establishing credibility is the identification and prompt dismissal of any bias that would undermine one's claims. Randomization emerges as a way to ensure that samples are not "cherry picked" to

[59] Jerome Cornfield, "Recent Methodological Contributions to Clinical Trials," *American Journal of Epidemiology* 104, no. 4 (October 1976): 408.

[60] Marks, 133.

weight the evidence artificially in favor of hypothesis confirmation. Double blinding serves a similar purpose. However, both serve as means of discharging moral responsibility and creating separation between clinician-investigators' fiduciary responsibilities and scientific virtues of clarity and credibility. The RCT itself is an attempt to wrest authority away from individual physicians as experts and allow the process of verification to proceed from a systematic and impartial foundation in statistics. Impartiality is subsequently affirmed as an epistemic virtue of both the machine bodies that produce the knowledge as well as the knowledge systems that analyze and control it.

One potential source of bias that encouraged the development of the industrial metaphor is the dreaded Type 2 error. Positive statistical identification of a Type 2 error indicates that an investigator has chosen too small a sample size to properly demonstrate that an effect is not due to chance. By seeking to avoid Type 2 errors and disprove the null hypothesis, investigators solidify the body of medical knowledge through experimentation using large sample sizes. Investigators are thus drawn to seeing persons as mere parts of a whole, whose function and purpose are only related to how they serve the scientific question. In this metaphorical understanding, it is not the individual that counts, but the aggregate. In order to become useful as a statistical body, the lived body must be homogenized.

The search for uniformity, generalizability, and statistical significance inevitably leads to the search for uniformity in bodies. In a classic case of widespread "physics envy," clinical investigators across the board "aspired to the conditions of the laboratory experiment, where ideally the factors that affected outcomes were both known and

manipulable."[61] This claim suggests that investigators needed to discipline bodies in order to get them to conform to the expected uniformity of data. Human bodies were seen as clinical material that could be molded into the shapes of working scientific objects and become as manageable as the lab rat or as passive as the petri dish. In historian Alexandra Minna Stern's view, "If the microscope and its appurtenances of slides and cultures exposed a hidden bacterial world which had previously existed only in the abstract, statistical methods and normal curves inductively abstracted from the concrete 'to a postulated reality' originating prototypes and endowing them with enough distributive power to stand for the whole."[62]

By the 1960s, the demand for large numbers of bodies reached a fever pitch. Universities across the nation were conducting research with the support of the federal government, especially the Department of Defense (DOD). Once again, the scandal that emerged due to a failure to oversee the testing, manufacture, marketing, and sales of a new drug was responsible for increasing the number of clinical trials. This time the culprit was thalidomide, a narcotic given to pregnant women to ease the symptoms of morning sickness and to help them sleep. Not long after it became a widely used medication in Europe, its teratogenic effects were discovered.[63] In response, the FDA took steps to increase the number of trials required before a drug could be marketed.[64] Hospital patients were no longer sufficient to meet the demand. Prisoners became

[61] Marks, 140.

[62] Alexandra Minna Stern, "Secrets Under the Skin: New Historical Perspectives on Disease, Deviation, and Citizenship. A Review Article," *Comparative Studies in Society and History* 41, no. 3 (July 1999): 589.

[63] Carl Zimmer, "Answers Begin to Emerge on How Thalidomide Caused Defects," *New York Times* (March 15, 2010).

[64] J.C. Krantz,,"New Drugs and the Kefauver-Harris Amendment." *Journal of New Drugs* 6, no. 2 (March-April 1966): 77.

"almost the exclusive subjects in nonfederally funded Phase 1 pharmaceutical trials designed to test the toxicity of new drugs."[65] In terms of how this metaphorical vision shaped the ethics of research using human subjects, it should be clear that investigators persuaded by this vision realized that if humans were nothing more than machines or factories of knowledge then there would be no reason to ask for their consent. Thus, one of the major ramifications of seeing bodies as factories is that informed-consent provisions were unnecessary. They were seen as especially unnecessary during wartime as any subjects who would dare to refuse would set back the course of medical progress.

PUTTING THE MACHINES TO WORK: A BRIEF HISTORY OF HUMAN RADIATION EXPERIMENTS

The following case histories illustrate how, during the Cold War, soldiers and prisoners were used as nuclear calibration devices for the United States military and for civilian agencies interested in protecting factory workers from exposure to dangerous levels of radiation. As participants in the military's investigation of the dangers of radiation, these men were seen by investigators and policymakers as a different kind of cannon fodder. They were not simply seen as disposable but also as valuable only insofar as they possessed bodies that could be used to discover thresholds of toxicity relative to harmful environmental elements. As regards the risks of acute and long-term injury due to radiation poisoning, "scientists had known from the earliest studies of radioactivity that radiation could harm living tissues," but the exact risks, thresholds of harm, and best means for testing the effects of radiation on human bodies were still matters of intense

[65] Advisory Committee on Human Radiation Experiments, *Final Report of the Advisory Committee on Human Radiation Experiments* (New York, NY: Oxford University Press, 1996), 273.

debate.[66] In most cases, animal models were inexact and therefore inappropriate. Therefore, human bodies were needed as tools of measurement. More specifically, investigators who orchestrated and participated in the various trials described below were searching for organic analogues for the mechanical dosimeter within the tissues and organs of the human body.

Most of the research studies I will describe in the following pages were not conceived as conventional clinical trials as now commonly practiced. For example, many did not use separate controls but followed subjects from baseline readings along the course of the study to determine the effects of the intervention being tested. Nevertheless, the uncertainty that the military and the Atomic Energy Commission (AEC) were dealing with is analogous to the uncertainty that clinical investigators deal with at the start of a clinical trial, especially Phase 1 trials. For the most part these studies were nontherapeutic—that is, they were designed to test the threshold levels at which deleterious effects might be measured in order to establish benchmarks for other uses outside of medicine. More specifically, the nuclear weapons tests described in the first part of this section were "designed to measure radioactive toxicity by inhalation and application to the body or clothing, its speed of action, its stability and danger, and how easily it penetrates protective devices."[67] In this sense, they most resemble modern Phase 1 trials of pharmaceuticals in that they were not organized to test the efficacy, but only the safety, of the intervention in question. In addition, these studies were supervised by, if not always performed by, medically trained personnel who received funding from

[66] David S. Jones and Robert L. Martensen, "Human Radiation Experiments and the Formation of Medical Physics" in *Useful Bodies: Humans in the Service of Medical Science in the Twentieth Century*, eds., Jordan Goodman, Anthony McElligot, and Lara Marks (Baltimore, MD: Johns Hopkins University Press, 2003), 83.

[67] Andrew Goliszek, *In the Name of Science* (New York, NY: St. Marten's Press), 118.

universities and government agencies in order to test what they believed were scientifically valid questions. The results of these trials were often printed in scientific journals and evaluated by scientific and medical peers. Though in these respects they may be similar to modern clinical trials, there are significant differences that will be revealed through the course of this chapter.

Historians David Jones and Robert Martensen have claimed that investigators during this time demonstrated through their "choice of research populations and the precautions they took [that] subjects would be harmed."[68] In all of the cases described below, investigators used what they understood as the biomechanical features of the human body as a means for calibrating other machines. In these cases, human bodies were used to challenge the conclusions reached and refine the data gathered through the use of mechanical devices that were used to sense the rate of atmospheric exposure to radiation. In addition, military commanders wanted to test the efficiency, effectiveness, and productivity of soldiers fighting near ground zero. They used medical data to model interventions to protect soldiers to the minimum degree necessary for them to continue functioning in their military roles. They were not considered as persons, but merely as the equivalent of modern-day crash-test dummies.[69] Under the industrial and mechanical metaphors mentioned above, the lived body was transformed into a scientific object that was in turn configured to test the body's capabilities as an instrument of national security. Medical science was employed in the service of testing how the web of instrumentality within which the human body is both tool and subject functions under duress. As the human machine body is the only instrument that may be feasibly used in these scenarios,

[68] Jones and Martensen, 84.

[69] Interestingly enough, the scientists at Los Alamos and Brookhaven National Lab used mannequins as stand ins for human subjects during some of their radiation experiments.

investigators during this time period fell into the trap of desiring to capitalize on the same kind of unique opportunity that also ensnared the United States Public Health Service in Tuskegee and German doctors in Dachau.

Throughout the Cold War, military preparations for possible attacks by the Soviet Union and its allies were being made by the United States and Great Britain. The British were mainly concerned with evaluating the potential impact of biological and chemical agents being dispersed from ships at sea and wafting across the British Isles. They ran a series of nonpathogenic biological weapons tests in order to estimate the potential effects of this kind of warfare. In his analysis of this weapons testing program, historian Brian Balmer notes that "the idea of the body as research material or research tool suggests a deliberate attempt to create subjects or measuring devices with people or parts of people … such attempts could readily be construed as a means of simultaneously producing knowledge about the body while exercising power over the body."[70] In fact, this was precisely the modus operandi of the American military during the Cold War nuclear weapons testing program in Nevada and other parts of the United States.

As participant-observers in these nuclear tests, soldiers' bodies were used by their commanding officers as embodied rhetorical devices. Their bodies served as organic dosimeters that could be used to verify the government's assertion that exposure to radiation levels below a certain threshold was safe. In an age where atomic power offered the possibility of endless energy supplies and medical breakthroughs, this appeal to the hopes and denial of the fears of the American public through the visual rhetoric embodied

[70] Brian Balmer, "Using the Population Body to Protect the National Body: Germ Warfare Tests in the United Kingdom After World War II," in *Useful Bodies: Humans in the Service of Medical Science in the Twentieth Century*, eds., Jordan Goodman, Anthony McElligot, and Lara Marks (Baltimore, MD: Johns Hopkins University Press, 2003), 43.

by fit and healthy American servicemen was key to keeping the American economy booming. To this end, soldiers themselves could spread the word about the safety of nuclear weapons to their fellow servicemen, thus boosting morale.

In 1951, Operation Buster-Jangle introduced ground movements using troops in a simulated nuclear battlefield into the pattern of atomic weapons testing, a trend which continued for the next eleven years. As the series of tests continued, each successive test brought troops closer to ground zero. These tests served several military purposes. First, close-up exposure to the effects and the spectacle of the atomic bomb were seen a kind of "emotional vaccination."[71] As mentioned above, military strategists had a strong interest in providing positive images of the tactical power of the American nuclear arsenal, which was not limited to military personnel. Second, for the purpose of persuading health officials that the tests were safe, the military pursued proof that atmospheric radiation dissipated and left no dangerous residue on the ground. Third, military leaders involved with the AEC sought to push the current "infinitesimal 'tolerance' doses used in industrial and laboratory practice towards vastly larger militarily acceptable doses."[72]

By the time Operation Tumbler-Snapper was initiated in 1952, troops were stationed only four miles away. It was at this time that physicians in charge of the AEC expressed their concern about the "serious adverse effects" of stationing troops too close to the blast.[73] In this instance, the military was able to overrule these concerns. Though the military claimed to be testing threshold doses for performance and safety, "many veterans were not issued film badges, and the records for some film badges are missing

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[71] Eileen Welsome, *The Plutonium Files : America's Secret Medical Experiments in the Cold War* (New York, NY: The Dial Press, 1999), 251.

[72] Ibid., 253. Quoting Gen. James Cooney, M.D.

[73] Ibid., 264.

altogether."[74] Furthermore, film badges could not measure alpha, beta, or neutron radiation. They were designed to measure only external radiation, not the absorption of radioactive particles through the lungs. According to the members of the Advisory Committee on Human Radiation Experiments (ACHRE), "[f]or numerous atomic veterans, the testimony [they gave] was not simply that the bomb tests themselves had been large experiments, but that they had been put at risk in the absence of planning to gather the data and perform the follow-up studies needed to ensure that the risks of the unknown, however small, would be measured and adequately accounted for."[75] The next series of tests would place troops even closer.

Officer volunteer groups during Operation Upshot-Knothole in 1953 were stationed 2,000 yards from ground zero. They were also required to calculate for themselves and their men how far they thought they could safely be from the nuclear detonation. Some were stationed as close as 1,500 yards from ground zero. These volunteers documented skin disorders, hair and teeth falling out, increases in cancer incidence rates, germline mutations, and other deleterious health effects.[76] Many internal exposures during these tests were "in the hundreds or thousands of rads, certainly high enough to cause concern regarding incidence of radiogenic as well as nonradiogenic disease."[77] Though hundreds of troops were exposed to dangerous levels of radiation, the debate about thresholds of toxicity was not settled—the laboratory was simply moved from the ground to the sky during the next series of tests.

[74] Ibid., 267.
[75] ACHRE, 303.
[76] Ibid., 266.
[77] Ibid., 269.

The protocol for Operation Teapot (1955) called for sampling of the radiation contained in the mushroom cloud of a nuclear explosion. Pilots' bodies were equipped with film badges for monitoring both internal and external radiation exposures. The goal was to determine whether the skin and exterior of the body would reduce the exposure of the internal organs to damaging radiation. Pilots were ordered to fly in and out of the cloud continuously for 15-45 minutes. After they landed, they rubbed their hands on the contaminated plane to test whether conditions were safe enough for ground crews to work on the contaminated aircraft. Urine and blood samples were taken, and the film badges that had been swallowed were removed and analyzed.

A second round of sorties through the mushroom clouds took place during Operation Redwing in 1956. Pilots during this operation were used to examine the ingestion hazard of air that had been ionized. Urine and blood samples were also taken.[78] The maximum radiation doses in the cloud were reported at 800 roentgens per hour.[79] Film badges revealed exposure to 15 roentgens. According to interviews conducted with the pilots many years following their participation, many "developed cancer or other diseases they feel were caused by their radiation exposure."[80] According to one of the test pilots, "The whole thing was fraught with peril and danger and they knew it was, and this I resent quite readily."[81] Both operations confirmed the theory that internal and external

[78] Incidentally, plutonium oxide, which is released during a nuclear blast, doesn't even show up in urine. See Welsome, 483.

[79] Edward Markey, *American Nuclear Guinea Pigs: Three Decades of Radiation Experiments on US Citizens* U.S. House of Representatives, Subcommittee of Energy Conservation and Power, Committee on Energy and Commerce, (October 24, 1986), 28.
http://www.gwu.edu/~nsarchiv/radiation/dir/mstreet/commeet/meet1/brief1/br1n.txt

[80] Welsome, 284.

[81] Ibid.

dose were essentially the same. These studies were of negligible scientific value, yet humans were used because only they could simulate real-life pilots' experiences.

During Operation Teapot and Operation Redwing, the bodies of the pilots used to fly through the mushroom cloud were clearly used as human Geiger counters. Each mission protocol called for pilots to swallow film devices attached to pieces of string so that they could be retracted, retrieved, and analyzed after flight. In so doing, investigators were using persons as hybrid organic/mechanized sensory devices. Like some kind of bizarre *matrioshki*, pilots' bodies, which were already seen as data-gathering machines, were enhanced by an extra set of internal "eyes."[82] In these experiments, the clinical gaze was quite literally internalized.

AEC and DOD investigators knew that radiologists exposed to radium, the metal upon which most calculations of tolerable doses were based, had experienced disfiguring injuries and untimely deaths from exposure to radiation. Given what was known at the time about the risks of radiation poisoning and the unpredictable and uncontrollable nature of atomic explosions, it is reasonable to suggest that investigators knew that some subjects might be injured. Their failure to carefully consider the evidence supporting the risks associated with the inhalation of radioactive particles translated into a failure to properly shield soldiers and civilians from potential disability and death. Nonetheless, finding the means to properly shield astronauts from the dangers of space radiation and in so doing ensure that America would win the race to the moon remained a priority. Fortunately for the clinician-investigators discussed in the following section, prisoners were as readily available as soldiers.

[82] Matrioshki are also known as Russian nesting dolls.

As the problems of space flight began to trouble the minds of the nation's scientists, in 1963 NASA and the AEC conducted a joint project to address concerns about how radiation would affect astronauts in space. The AEC was asked to determine the maximum amount of radiation pilots could tolerate without long-term damage to their reproductive capabilities. According to testimony from one of the prisoner-subjects who eventually sued the AEC, "they wanted to discover the maximum dosage that creates no tissue damage and they wanted to find the minimum dosage that produces permanent damage."[83] The testes were chosen as a "mechanism to measure the effect of ionizing radiation on the human body" because they could be irradiated without irradiating other parts of the body and because they are the "most radio-sensitive organs." [84]

The AEC selected Dr. Carl G. Heller, a well-known endocrinologist with no experience in radiation medicine, who devised the protocol and made arrangements to recruit inmates at the Oregon State Penitentiary. From 1964-1971 he irradiated the scrota of sixty-one prisoners in order to determine the minimum dosage necessary to cause "permanent damage."[85] His protocol called for testing dose-dependent toxicity, which meant that the dosage administered each time would increase by fifty roentgens. Each prisoner received anywhere from eight to six-hundred rads per dose via an x-ray machine built by Dr. Heller expressly for this purpose.[86] Modern medical evidence indicates that

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[83] Harold Bibeau, testimony at Spokane Meeting of ACHRE outreach groups, (November 21, 1994), accessed November 26, 2012, http://www.gwu.edu/~nsarchiv/radiation/dir/mstreet/commeet/pm02/pm2trnsa.txt

[84] ACHRE, 265; and Carl G. Heller, Daniel DiIaconi, Mavis Rowley, "Protection of the Rights and Welfare of Prison Volunteers: Policies Followed Throughout a 17 Year Medical Research Program" US Department of Energy, Office of Scientific and Technical Information, accessed September 28, 2012, https://www.osti.gov/opennet/servlets/purl/16291610/16291610.pdf .

[85] Welsome, 365.

[86] See Goliszek, Welsome, and ACHRE. An average chest x-ray is equal to 0.0025 rad. A roentgen is the measure of the ionization produced in air by gamma radiation. It is not a measure of

exposure above 150 roentgens "would increase the risk of leukemia by a factor of seven and double the risk of many other cancers."[87] In terms of the acute short-term risks of harm, Heller claims that subjects were informed that they might face "skin burns, pain from biopsies, orchitis induced by repeated biopsies and bleeding into the scrotum from the biopsies."[88] Apparently these risks were not enough to deter prisoners from offering their bodies to medical research.

Like many of their brethren in prisons across America, prisoners of Oregon State Penitentiary were enticed to enroll into Heller's trials by the promise of small cash payments. Each radiation session paid $5 to $10, while Dr. Heller earned $1.12 million in grant money for the entire project.[89] In addition, prisoners could hope to receive narcotics as part of the anesthetics offered during their testicular biopsies. If a little spending money and some free drugs were not enough, prisoners also could have looked forward to being treated by Heller and his colleagues "as men not 'subjects.'" [90] Heller asserts that each subject was thrilled to spend some quality time with him and his staff, an opportunity they would not otherwise have had. He claims that these men were talked to and their personal feelings were known in some depth.[91] Because of his supposedly outstanding rapport with the prisoner-subjects, Heller believed that he could claim that the inmates at Oregon were "perhaps the best informed human volunteers in existence."[92] Of course, it is hard to take these assertions seriously in light of other comments Heller

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absorbed dose. A rad is the energy absorbed per unit mass. Air and soft tissue will absorb about the same number of energy, which is why rads and roentgens are used interchangeably.

[87] Welsome, 320.

[88] ACHRE, 266.

[89] Welsome, 367,

[90] Heller et al., "Protection of the Rights and Welfare"

[91] Ibid.

[92] Heller et al., "Protection of the Rights and Welfare"

made about his conversational partners. In a 1965-1966 progress report on the radiation experiments, "Heller boasted … that he had access to a 'virtually 'inexhaustible' supply of fresh testicular biopsy material from physically normal men."[93] This giddiness about his ability to use the bodies of these men to pursue his own scientific goals seems to clash with the way he claims to have treated his subjects.

Perhaps the most controversial aspect of Heller's experimental protocol was the requirement that subjects had to agree to a vasectomy upon the completion of the trial so as to avoid "contaminating the general population with irradiation induced mutants."[94] While his suspicions about potential germline mutations seem reasonable, it is unlikely that he would force subjects in the free world to undergo such a life-altering procedure. Since the bodies of his subjects were nothing more than machines to be manipulated, a mechanical fix would clearly be the only reasonable solution. It did not matter to him that such a move would arbitrarily limit the reproductive freedom of the inmates for the sake of trivial scientific knowledge. To make matters worse, Heller had each subject screened by a psychologist, who asked them about their reproductive plans. This testimony was then used to justify the requirement for these men to undergo an unnecessary procedure. To Heller and those who allowed these violations of human dignity to occur, these men were clearly nothing more than machines whose parts were of no importance beyond their scientific value. To Heller's mind, a vasectomy must have seemed as innocuous and as logical as switching off a light bulb when one leaves the room. Unfortunately, the mechanical metaphor permitted Heller to think that the fertility of these men was something that could be switched on and off just as easily.

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[93] Welsome, 371.
[94] Heller et al., "Protection of the Rights and Welfare"

In his defense, Heller argued that it seemed to him "far more unsound ethically to carry out investigations utilizing non-institutionalized individuals before chromosomal dangers or reproductive changes (resulting in possible abnormal births) have been worked out on humans who cannot cause conception because of their isolation from general society."[95] In other words, he seems to be arguing that since these people are less valuable, their reproductive health is less important. More importantly, his remarks imply that since their reproductive abilities are constrained by their imprisonment, it is therefore reasonable to use these constraints to his advantage. The question then becomes one of utility and convenience. In a typically paternalistic comment in a paper written as a kind of apologia, Heller claimed that inmates saw this free and, at the time irreversible, medical procedure as a benefit.[96] Most of his fellow interlocutors would have disagreed.

The majority of the sixty-one inmates who participated in what came to be known as the Heller Experiments and subsequently spoke out about their treatment were outraged by Dr. Heller and his staff's indifference to their suffering and humiliation. In his deposition for one of several lawsuits filed against Heller and his associates, Baxter Hignite noted, "Most of the times it felt like he took a pair of pliers and pulled a chunk of meat off my testicles. That's the kind of pain I would feel."[97] Another inmate, Harold Bibeau, who filed a series of unsuccessful lawsuits against Heller and the Pacific Northwest Research Foundation, alleged that "as a result of the experiments, he suffers from intermittent pain and rashes on his scrotum and groin, pain from the biopsies, as well as severe emotional distress. He also alleges that he suffers from a significantly

[95] Heller et al., "Protection of the Rights and Welfare"
[96] Ibid.
[97] Welsome, 370.

increased risk of developing cancer and other serious illnesses. As a result, he requires medical monitoring."[98]

Another inmate, Paul C. Tyrell, who also filed a lawsuit on behalf of his fellow inmates, alleged that he was "enticed and coerced by the defendants to participate in a medical experimentation."[99] He claimed that he was "administered large doses of lethal radiation which were applied by an unlicensed prison inmate to his testicles on at least two occasions."[100] He also claimed that he notified the defendants in the lawsuit about the extreme pain he was in and told them that he thought he had not received adequate anesthesia during the biopsies. After his participation in the experiments, he experienced "soreness and pain of the scrotum, rashes, sores and peeling of the scrotum, and knots and adhesions of the testicles and severe mental anguish."[101] He also traces the following sequelae back to his participation: "extreme nervousness, pain in various joints, loss of secondary sex characteristics and sterility, blurriness of vision, malignant breast tumor and subsequent removal of his breast, loss of hair growth on his face."[102] Furthermore, he claimed the experiments were unjustified and that the defendants, especially Heller and DiIaconi, knew of the likelihood of severe side effects.

Although these long-term effects are troubling in themselves, subjects also suffered from the disillusionment with the medical profession that their participation in these trials engendered. According to Bibeau, "they zapped us with dosages that were high enough to cause burns and blistering to the groin of the legs and hair loss to the

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[98] Bibeau vs. Pacific Northwest Research Foundation, 339 F.3d 942, (9th Cir., 2003).

[99] Nikolaus Albrecht, Civil Case Complaint, Paul C. Tyrell v. State of Oregon, et al. United States District Court, District of Oregon, (May 1976), Department of Energy, accessed November 25, 2012, https://www.osti.gov/opennet/servlets/purl/905207-QuF0lE/905207.pdf.

[100] Ibid.

[101] Ibid.

[102] Ibid.

entire groin area, they sliced us open and took testicular biopsies; and when we left prison no longer able to sire children and no longer of any value to them, they cut us off with nothing to show for our efforts except everlasting pain and $100. I really don't think it was worth it."[103] The labor that the bodies of these prisoners contributed was not only undervalued, but also the persons who supplied their bodies were disvalued. If a mechanical body is only valued as long as it is serving the purpose of the user of that machine, then there would be no reason to care for it after the task has been completed. By treating these men like machines, Heller and his colleagues are responsible for disenfranchising them from the system of health care. Bibeau and others clearly felt a sense of betrayal and abandonment. In another part of his statement to ACHRE, Bibeau declared, "men that I'm coming in contact with today are still experiencing pain, they have grave doubts about their futures, and their pleas for help are being ignored by the monsters who participated in abuse of their bodies."[104]

Heller was clearly aware of the tendency for male subjects to resist repeated biopsies, continuous submission of bodily fluids for testing, and the daily ingestion of medicine. However, he did not bother to introduce these considerations into his experimental protocol. In a study on the effects of progesterone on the physiology of normal subjects, Heller outlines these concerns and shows how using prisoners made them insignificant.[105] According to the results of this earlier study, subjects suffered from "azoospermia, complete loss of libido, a marked reduction in potentia, and an alarming

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[103] Harold Bibeau, testimony at Spokane Meeting of ACHRE outreach groups, (November 21, 1994) http://www.gwu.edu/~nsarchiv/radiation/dir/mstreet/commeet/pm02/pm2trnsa.txt.

[104] Ibid.

[105] Carl G. Heller, Donald J Moore, C. Alvin Paulsen, et al. "Effects of Progesterone and Synthetic Progestins on the Reproductive Physiology of Normal Men" *Federation Proceedings* 18 (December 1959): 1057-65.

decrease in testicular size."[106] His familiarity with these side effects and the responses that these subjects surely must have given to him in this earlier study apparently had no effect on how he treated the subjects of the radiation experiments. As an endocrinologist, Heller should have chosen a urologist and a genetic counselor to join him in his research, since these specialists could have offered further insights into the subjective experience of interventions involving highly sensitive and symbolically important areas of the human body.

It is clear from the experimental evidence that Heller saw prisoners as mere biological objects who, unlike other mammals, just happened to have a unique ability to "submit to serial testicular biopsy without damage and biopsy-induced testicular artifacts."[107] Of course, this assumption was proven false as a result of these tests. Furthermore, despite his testimony to the contrary, he clearly reduced these men to their body parts. Although each prisoner was a unique person who happened to be embedded in a social context that was oppressive, violent, and chaotic, each still possessed the capacity for love, romance, and masculinity. Instead, following a long legacy of demonization and degradation experienced by imprisoned populations, these men were treated as the basest of animals. As journalist Eileen Welsome notes, it was ironic that "after military and civilian experts had spent many years and hundreds of thousands of dollars, Heller believed he had found the ideal dosimeter: human testicles."[108] His recommendation following the publication of the results of the radiation experiments was for industry to adopt biopsies as a routine matter for radiation workers. He argued that the best way to monitor the safety of the atomic workers was to take biopsies after their

[106] Ibid.
[107] ACHRE, 279.
[108] Welsome, 375.

exposure to predict the levels of radiation absorbed. Clearly, his view of the bodies of others as mere machines was not limited to the bodies of prisoners.

Despite the testimony of the prisoners he treated as mere means, Heller claimed to be concerned about the reproductive health of his subjects. He alleged that part of the research was the "development of an agent which would allow infertile men to become fertile and the development of male contraceptive agents."[109] There is no evidence that the former was even considered in any of the published materials on the experiments, though the latter was certainly a byproduct of the studies. Given the nature of the experiment, the population used, and the testimony of the prisoners who participated, there may be reason to suspect that Andrew Goliszek's controversial assertion that "the study was really a sterilization experiment" may have some merit.[110] While a eugenic intent was likely not at the forefront of Heller's thinking, it is clear from the experimental design that periods of sterility were one of the endpoints Heller wished to test.

As for scientific impact, no new breakthroughs were to emerge out of Heller's research. His findings were fairly unspectacular. The sacrifices of these prisoners led to the discovery that human germinal tissue was, in fact, more sensitive than tissue from other mammalian species. In fact, the testes were excellent dosimeters. Unfortunately for Heller, it would have been wildly impractical and inappropriate to use them as such. For these results, subjects received a few dollars and "rashes, peeling, and blisters on their scrotums. In the months and years following the exposure, many also said that they experienced pain during sexual intercourse, had difficulty maintaining erections, and their

[109] Heller, et al., "Protection of the Rights and Welfare"
[110] Goliszek, 138.

testicles shrank in size."[111] In effect, Heller emasculated his subjects, weakened their ability to express themselves sexually, and shrank their sphere of influence as men.

While a full account of the medical experiments that were conducted on patients would be beyond the scope of this dissertation, a short synopsis of the so-called "Boston Project" conducted by the AEC and Dr. William Sweet at Massachusetts General Hospital should give the reader a sense of how patients were also used as nuclear calibration devices.[112]As mentioned above, medical research using human subjects during wartime and following World War Two was characterized by a fascination with the novelty of radiation as a potential magic bullet for medical treatment. In pursuit of these ends, terminally ill and comatose patients were injected with uranium in order to find threshold levels of toxicity. The unstated aim of these studies was to bring these bodies to autopsy and harvest samples including "a whole femur, a whole kidney, and large pieces of liver and spleen, and a sagittal half of kidney, in addition to pieces of all other organs."[113] The Boston Project serves as an example of how live bodies at the edge of death were used as measuring devices to protect the bodies of uranium miners and atomic weapons workers from injury or harm. In truth, these studies were conducted to maximize productivity by allowing supervisors to expose workers to sources of radiation poisoning up to the maximum levels permitted before giving them a break. The committee responsible for overseeing this research was not primarily concerned with the

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[111] Welsome, 370.

[112] Gilbert Whittemore and Miriam Boleyn-Fitzgerald, "Injecting Comatose Patients with Uranium: America's Overlapping Wars Against Communism and Cancer in the 1950s," in *Useful Bodies: Humans in the Service of Medical Science in the Twentieth Century*, eds., Jordan Goodman, Anthony McElligot, and Lara Marks (Baltimore, MD: Johns Hopkins University Press, 2003), 171.

[113] Whittemore, 171.

"protection of the subjects but [with] the safety of the researchers."[114] As with some of the other studies described above, Dr. Sweet and colleagues followed a poorly constructed methodology. Since their lab techniques for delivering and measuring the uranium had not been perfected in animals, measurements were not made accurately. In most cases, they were simply calculated from the excretion data to give the initial injection amount.[115]

As this section has shown, both military and civilian investigators saw the body of the Other as a mere machine that could be manipulated and made to serve the interests of medicine and the military. As Edward Markey's groundbreaking report notes, "Although these experiments did provide information on the retention and absorption of radioactive material by the human body, the experiments are nonetheless repugnant because human subjects were essentially used as guinea pigs and calibration devices."[116] The ethical problems surrounding the use of humans as mere means did not escape the members of ACHRE. In their final report, they note that "although it is always morally offensive to use a person as a means only, as the burden on the patient-subject decreased, so did the seriousness of the wrong."[117] This criticism is far too permissive of the use of persons as mere means. In truth, it shows a lack of sensitivity among the bioethicists who made up ACHRE to the problems of using persons as mere means in any case, no matter what the degree. The burden of proof for using the body of another and treating it as an object should always be on the intent and the nature of the relationship between the individuals involved. Placing these debates on the scale of policy or allowing them to be diluted by

[114] Whittemore, 175.
[115] Ibid.
[116] Markey, "American Nuclear Guinea Pigs"
[117] ACHRE, 220.

appealing to the degree of the burden placed on the subject is a mistake that allows investigators to continue to see persons as objects. What is needed is a broadening of the moral vision of investigators. A Boston Globe article written in response to the ACHRE report criticizes this diluted moral standard on the grounds that it "lets government off too easily, for it does not assign blame based on the essential nature of the action itself—the use of an innocent person as a test animal—but rather fosters a retrospective opinion that allows less-bad outcomes to ameliorate the action's inherent wrong."[118] If the Cold War was a "time when certain medical doctors acted like predators and viewed their patients as little more than white mice," then something needs to be done to reeducate the foxes before we let them guard the henhouse again.[119]

THE COMMODIFICATION OF THE IMPRISONED BODY

Among the more degrading metaphors used by investigators during the twentieth century are those that compare human research subjects to agricultural commodities. These metaphors trade on the instrumental value of bodies as goods that have only economic or social value. One of the milder metaphors commonly found in the scientific literature is the phrase "adding to our storehouse of knowledge."[120] Investigators often use this term as a way to describe the benefits of research. At first glance, this notion of a "storehouse" as a comparison between the body of knowledge contained within the scientific literature and a place where commodities are stored seems harmless. However, one of the implications of this metaphor is that the human bodies that produced this knowledge are less valuable than the knowledge itself. By way of comparison, a field of

[118] Welsome, 465.
[119] Welsome, 486.
[120] Rothman, , 54.

wheat is only economically valuable if it produces grain that may be harvested and turned into something else. Investigators during the historical episodes described below seemed to have taken the biblical exhortation to heart and placed themselves in charge of separating the wheat from the chaff in order to serve up more "human grist for the research mill."[121] In this section, I will trace out the moral and epistemic implications of the agricultural metaphor. As one of the foundational images of human research using prisoners, this metaphor compares the production of medical knowledge to a crop being harvested from a field. In this case, this metaphorical field is composed of living human bodies. I will focus my analysis on the experiments conducted by Dr. Albert Kligman and his staff on the inmates at Holmesburg Prison outside of Philadelphia, Pennsylvania, from 1951 through 1974, though one additional case study not related to Kligman's work will be offered at the end of this section. Before I begin this analysis, however, it will be helpful to discuss some of the social significance of what I will refer to as the "agricultural metaphor."

The historical evidence presented below will show that prisoners in these experiments were not considered to be persons or even beings who were worthy of respect. First, questions about their ability to freely consent were raised and summarily dismissed by investigators more interested in making scientific breakthroughs than protecting human subjects. Exculpatory language was used in what passed for consent forms. The use of this language implied that prisoners were already devoid of legal standing and devoid of personhood, yet investigators retrospectively referred to these as genuine consent documents. Second, experiments that never would have been done on

[121] Allen Hornblum, *Sentenced to Science: One Black Man's Story of Imprisonment in America* (University Park, PA: Penn State University Press, 2007), 8.

persons outside the prison walls were conducted with impunity. Third, many of these experiments were dangerous and caused both short-term and long-term injuries, as well as loss of dignity, and reinforced assumptions about prisoners' bodies and their value to medicine and society. Fourth, the system of compensation was manipulated according to a market that was isolated from the social values that determine the market value for goods and labor outside prison walls, thus artificially devaluing both prisoners' bodies and prisoners' labor.

The commodification of bodies is a central aspect of Kligman's research. The agricultural metaphor supplied him with the ideology necessary to commodify the body, "which depends on being able to regard it as other, alienable from the essential self."[122] Money flowed freely from his contracts with governmental and industrial sponsors. His affiliation with the University of Pennsylvania afforded him financial and institutional support that allowed his research program to grow and blossom, albeit without supervision by the executives within that or any other organization. Some of his pharmaceutical sponsors made the direct connection between productivity and the commodification of prisoners' bodies. They argued that "research labs could be considered an extension of the prison work shops and other activities geared to the rehabilitation of prisoners."[123] This combination of a rhetoric of productivity with a rhetoric of labor as redemptive was based on the assumption that prisoners had no value in themselves and no ability to rehabilitate themselves by turning inward or finding other sources of inspiration. Under a rhetoric of productivity, once prisoners were placed

[122] Drew Leder, "Whose Body? What Body? The Metaphysics of Organ Transplantation," in *Persons and Their Bodies: Rights, Responsibilities, Relationship*, ed. M. J. Cherry (Dordrecht, Netherlands: Kluwer Academic Publishers, 1999): 244.

[123] Allen M. Hornblum, *Acres of Skin* (New York, NY: Routledge, 1999), 103.

outside of society yet supported as wards of the state they become mere vegetative beings who received nutriment and shelter from the state but produced nothing, with no inherent teleology other than to reform themselves. In fact, once incarcerated they became barren fields whose soil was corrupted by their past sins. In this light, prisoners' bodies were seen as spoiled and needing cultivation in order to be replanted in society. In many cases, bodies that would never have been permitted to return to productivity outside the prison walls were used, thus reinforcing the argument that these populations were chosen to participate because medical experiments were their only means of becoming useful to society. On this fallow ground, prisoners' bodies became hotbeds for diseases, including cancer, malaria, syphilis, and influenza.[124]

Albert Kligman set the tone for all subsequent discussions of his treatment of the prisoners who served as research subjects in a 1966 interview. When asked about his initial impression of the inmates at Holmesburg Prison, Kligman responded, "All I saw before me were acres of skin. It was like a farmer seeing a fertile field for the first time."[125] What followed this statement in terms of how he treated his subjects seems to confirm this view. Note that Kligman did not see people as he gazed out over the inmates' bodies, only the potential for unlimited research using freely available material. From this statement, one can infer that he had no sense of either the cost in terms of pain and suffering that his experiments would exact or of the intrinsic value of the persons to whom these acres of skin belonged. Kligman was clearly not alone in this view. As Allen Hornblum notes, "the doctors who entered Holmesburg Prison a few short years after Nuremberg were conditioned to see the mass of idle humanity before them as a 'fertile

[124] See Hornblum Ch. 3, 75-95.
[125] Hornblum, 37.

field' of investigatory opportunity."[126] Indeed, it is the persuasiveness of this rhetoric of reductionism and commodification that made these heinous experiments possible. Based on most of the accounts given by the prisoners and some of the staff who worked with him, Kligman "wasted no time cultivating and harvesting his acres."[127]

Prior to his arrival at Holmesburg "farm," Kligman started his career in human experimentation by investigating ringworm in children labeled as "mental defectives."[128] In the scientific publication that documented his study, he referred to his test population as ideal, since "biopsy material was freely available."[129] In other words, the children were seen as nothing more than tiny fields of skin to be harvested, as a biopsy is a kind of harvesting of tissue. Reviews of his article by prominent men in the field endorsed his view that institutionalized populations were ideal for dermatological research. Fortunately for these children, he could not use them as biopsy material forever. Soon he would move on to another fertile field of biopsy material.

In the same interview in which he expressed the agricultural metaphor under discussion in this chapter, Kligman went on to describe his discovery of Holmesburg as "'an anthropoid colony, mainly healthy' under perfect control conditions."[130] His smug sense of superiority is clearly expressed in his characterization of the inmates he saw as "anthropoid" but not fully human. To his mind, these inmates were something less than human, but humanlike. They were just human enough to be useful for his purposes.

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[126] Hornblum, 236.

[127] Hornblum, xx.

[128] Albert M. Kligman and W. Ward Anderson, "Evaluation of Current Methods for the Local Treatment of Tinea Capitis," *Journal of Investigative Dermatology* 16, no. 3 (March 1951) : 155-168; and Albert M. Kligman, "The Pathogenesis of Tinea Capitis Due to Microsporum Audouini and Microsporum Canis," *Jounral of Investigative Dermatology* 18, no.3 (March 1952): 231-46..

[129] Hornblum, 34.

[130] Hornblum, 37.

Living as they did in a colony, like a beehive or an undeveloped primitive community, these native anthropoids could not have realized at the time that their land was ripe for colonization by medical science.

Before one can judge the quality of the crop, one must first evaluate the quality of the seeds that have been planted. As a farmer working the fields of skin, Kligman had a hand in projects ranged from the mundane to the bizarre. Some descriptions of the experimental studies he devised conjure up the ghosts of Frankenstein or Dr. Josef Mengele. Some seemed outright sadistic, such as the fingernail extraction "study" that paid prisoners fifty dollars per fingernail. When presented with this proposal, inmates were shocked yet some agreed to participate, albeit only after negotiating for triple the original offer. One inmate involved suspected that the doctors were interested in "the wound, [how a] manhandled finger reacted to abuse."[131] To my knowledge, no scientific paper was ever published on the rationale or the results of this study. Another bizarre and sadistic experiment involved the insertion of two pieces of gauze subcutaneously into inmate Withers Poton's body.[132] These were left in and subsequently removed after two weeks. No explanation was given to Withers as to the purpose of the experiment or the results. Besides odd surgical interventions, Kligman and his staff of civilian and inmate assistants also injected prisoners with herpes and other viruses.[133] Some prisoners were injected with these viral agents several times on the same day in different areas of their bodies. In a series of separate trials, others were injected with phototoxic drugs and given staph infections and other skin diseases.

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[131] Hornblum, 15.

[132] Hornblum, 10.

[133] H. Goldschmidt and A. M. Kligman, "Experimental Inoculation of Humans with Ectodermotrophic Viruses," *Journal of Investigative Dermatology* 31, no.3 (1958): 175-182.

Another of Kligman's more bizarre and heinous clinical studies involved a hypothesis about skin hardening for battlefield protection using abrasive and toxic chemicals. Military officials were apparently interested in finding ways to protect soldiers beyond the standard helmet and body armor in use at the time. Following up on this interest, Kligman designed a protocol that involved coating prisoners' arms and hands with a variety of substances including hexane, benzene, hydrochloric acid, and sodium hydroxide. Application of these substances to the face and forehead caused severe inflammation and scarring. Some prisoners were permanently scarred by these tests. At the time, they were told that they would be participating in "soap studies."[134]

One of the more well-known of the countless tests that Kligman performed on the bodies of prisoners was the so-called "patch test." The rationale given for conducting this series of tests was to improve the sensitivity of bioassays for allergens. Essentially, this means that Kligman used human subjects to improve the testing methodology of dermatological research. These tests involved placing a whole slew of benign and extremely toxic materials on the backs, forearms, and legs of prisoners, covering them up with gauze and sealing the bandages with a liquid sealant. These investigational materials included ingredients in soaps, detergents, lotions, and other household products. Some of these patches were then exposed to sun lamps. On the more dangerous end of the spectrum, Kligman used known carcinogens like benzene, hexane, and dimethyl sulfoxide. Each substance tested was prepared and applied to the skin in concentrations

[134] Hornblum, 145.

that "[bore] no resemblance to normal use."[135] There was no discussion of the possible long-term effects of exposing these men to such dangerous substances.

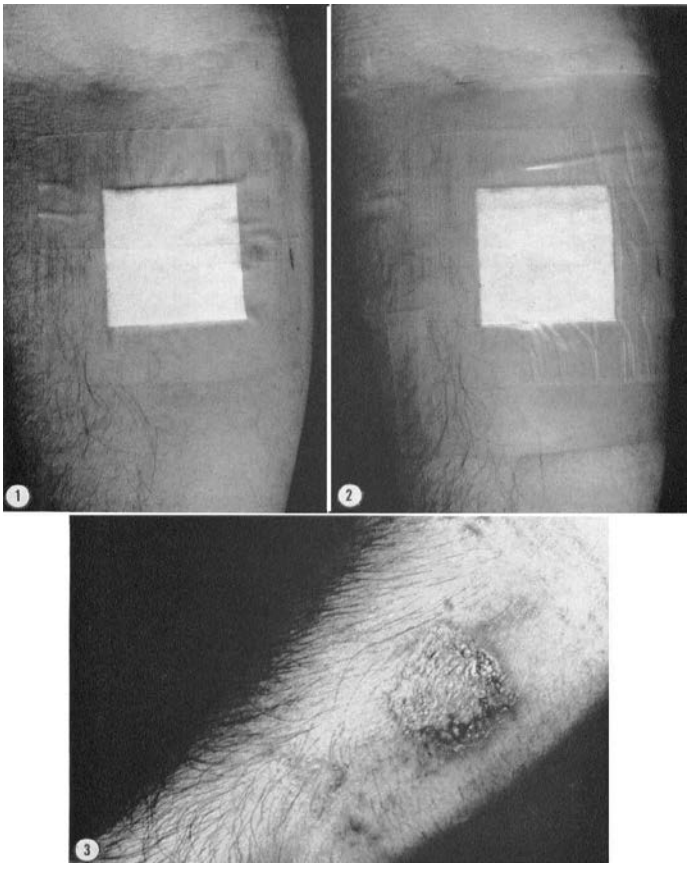

Figure 1: Albert M. Kligman, [Photograph of patch test sequence]. Reprinted by permission from Macmillan Publishers Ltd. from "The Identification of Contact Allergens by Human Assay" *Journal of Investigative Dermatology* 47, no.5 (November 1966): 395.

[135] Albert Kligman, The Identification of Contact Allergens by Human Assay: 3. The Maximization Test: A Procedure for Screening and Rating Contact Sensitizers." *Journal of Investigative Dermatology* 47, no.5 (November 1966): 404.

The fruits of Kligman's labors are apparent in the photographs he attached to his manuscript. Although most of his subjects were black, the photographs included in Kligman's article show the underside of the forearm of a white man being dressed in the manner described by him in the article (Fig. 1).[136] These photos show a disembodied arm in close up, with patches secured by tape on the skin. Within the figure shown above, the photos marked 1 and 2 do not show the wound inflicted by Kligman's test, but the photo marked 3 reveals a wound on the outside of the forearm. Though the footage is not in color, it is clear from the photo and the caption that the wound is oozing pus. There also appear to be signs of skin irritation, likely from the tape used to cover the patch. Unlike the article itself, there is no visual record of how the subjects tolerated the procedure, except through the wound itself. Instead, the viewer is presented with the body of the subject positioned as a grotesque and disembodied figure. In its desire to focus only on the relevant facts, the clinical gaze has quite literally been narrowed to the point of myopia. The choice of which prisoner to photograph is interesting for what it leaves out. Though one could argue that the choice to include a light-skinned prisoner instead of a darker-skinned inmate was an aesthetic decision made in the interests of highlighting the scientifically relevant features of the experiment, one could also interpret this choice as a desire to hide from public scrutiny who the majority of the subjects were. Perhaps in a moment of shame and contrition, Kligman wished to show that light skinned bodies had been used as well in order to deflect social condemnation. Or one could argue that the bodies of dark skinned persons were thought to be less indicative of normal, healthy bodies according to the clinical community and, therefore, using these bodies as illustrations would have diminished his credibility. Whatever his methodology may have

[136] Ibid., 395.

shown the scientific minds of his peers, the visual records of his experiments paint a portrait of an individual whose moral vision had been corrupted.

It is clear from the scientific literature and historical evidence that Kligman's methodology was often slipshod. In his published report, Kligman admits overdosing some subjects, which caused them to experience, "tachycardia, headache, nausea, vertigo, and altered emotions."[137] He also mentions how his efforts to save time and money led him to test multiple compounds at the same time on different parts of the body. Though he was cognizant of the risk of prisoners experiencing adverse reactions upon subsequent contact with the substances being tested, he dismissed this risk as insignificant. He also acknowledged the need for a large subject pool, but claimed he could achieve the same results with a much smaller sample. It is likely that with a larger pool, fewer substances could have been tested per subject, thus decreasing the risk of adverse reactions and improving the accuracy of the results. As regards the subject pool, Kligman mentions that it would not have been practical to use children, women, or the elderly. Although these populations are not all necessarily vulnerable, it is curious that Kligman would feel he needed to explain why he excluded them, but not why he decided not to use other healthy subjects outside of prison. Like many others, he claimed that prison populations "are ideal since strict controls can be exerted," yet by all accounts of the prisoners used in this and other trials, noncompliance, incompetence on the part of inmate assistants, and violations of the protocol were commonplace.[138] In fact, Kligman chose this population because he recognized that these bodies were both unworthy of respect and were already disciplined by the institution in which they were housed.

[137] Ibid., 404.
[138] Ibid., 396.

In terms of how subjects tolerated the patches, Kligman claims in the article he published on the results that the subjects usually "tolerate[d] the procedure with little complaint." [139] However, it is clear from the historical evidence that the physicians under his supervision did not provide care when complaints were made, that he was only on the experimental block two days of each week, that adverse events were hidden from the laboratory record, and that many prisoners were unwilling to report adverse events because they feared being dismissed from the protocol. Indeed, the testimony from prisoners tells a very different story. Yusef Anthony was one of the twenty-five prisoners who took part in the patch test. Shortly afterward, he felt like his back was on fire and passed out from the pain. His cellmates helped him take off the patchwork and placed it on the walls of the cell. Anthony then broke out in painful blisters and promptly sought medical attention from the University of Pennsylvania staff, as he had been instructed. On his account the "doctor didn't treat me at all" when he showed up in pain. [140] In his words he "looked like a goddamn strawberry" but could not get any medical attention from the University of Pennsylvania staff because he was taken off of the trial due to the adverse reaction he experienced.[141] Anthony could not sleep or get comfortable for weeks. Placed in an environment that is already oppressive and dangerous, sleep deprivation only increased his misery and made life unbearable for his cellmates as well. Anthony's scars and blisters also ostracized him from his social group. His appearance scared other prisoners and created tension in the social hierarchy. Others threatened by his appearance thought he might have contracted a contagious disease and threatened him

[139] Ibid.
[140] Hornblum, "Sentenced to Science," 5.
[141] Ibid., 5.

with bodily harm. For that reason he was placed in isolation away from his peers, which deprived him of the kind of social interaction that made prison life bearable.

Kligman's experiments with dangerous and potentially carcinogenic materials did not end with the patch test. As part of the industrial-academic partnership he engineered between the University of Pennsylvania and Dow Chemical Corporation, Kligman arranged to test TCDD (2,3,7,8—tetrachlorop-dibenzodioxin), a very potent carcinogen and a byproduct of herbicide production. The reasons given in Hornblum's account of these trials were pseudoscientific in that Kligman was asked to determine the thresholds of toxicity to prevent the EPA from banning this substance, which would mean that Dow would lose money. Previous animal testing and accidental exposures in humans indicated that TCDD caused chloroacne. Subjects' backs, foreheads, and forearms were rubbed with a mixture of either TCDD or hexachloral diphenol oxide, another known cholacnegen.[142] Kligman's first study showed no reaction to the chemical. He then increased the dosage without Dow's approval. This arm of the trial produced results, but Kligman refused to treat the severe skin irritation that developed. In total, Kligman unilaterally increased the dosage until the final dose given was 468 times stronger than the initial dose.[143] Prisoners claim that dioxin was actually injected, not just rubbed into the skin. After these seeds of science were planted, Kligman would harvest acclaim, money, and all the trappings of scientific achievement while the subjects who participated would only reap sorrow and suffering.

The testimony of the prisoners who survived Kligman's experiments is almost uniformly negative. Though many appreciated the chance to make some extra money, as

[142] Ibid., 168.
[143] Ibid., 169.

it kept them out of the reach of sexual predators and away from some of the harsher aspects of prison life, the scars that their participation left them with brought them anger and bitterness. In fact, the rhetoric of reductionism was so prevalent in the institutional environment that many of the former prisoners adopted new and disparaging metaphorical representations of themselves and their bodies.

One inmate who was very active in advocating for compensation and follow-up treatment, Leodus Jones, told one reporter that, "I look like a pinto pony on some parts of my body."[144] Leodus suffers from permanent skin discoloration and frequent rashes all over his body. His body will forever be marked as a colonized space. Like an animal, he has been branded with the mark of his history as an object of study and as an object that has been dominated by the power relations of clinical investigators who neglected his humanity. Kligman and his associates clearly displayed blatant disregard for the body schema, self-image, and the sanctity of prisoners' bodies. It is ironic that a dermatologist, whose scientific domain is the most visible organ of the human body, would be so indifferent to the possibility of permanently disfiguring someone else's body. Even if these men never reentered society, their life in prison is forever tainted by the discoloration of their skin. In a space with limited possibilities in terms of how bodily intentionality is constructed, social hierarchies are extremely important and are often determined by skin color and other stories told by the body.

Other subjects had similar stories to tell. Allan Hornblum's *Sentenced to Science: One Black Man's Story of Imprisonment in America* tells the story of Yusef Anthony, who participated in several of Kligman's experiments, including the patch test mentioned

[144] Marie McCullough, "Former Prison Inmates in Pennsylvania Protest Skin Doctor's Award," *Philadelphia Inquirer* (October 30, 2003).

above. Anthony continues to suffer from episodes where his skin becomes so "sensitive that he can't peel an orange without developing an agonizing internal itch that only scalding hot water will soothe."[145] These episodes began shortly after his back was marked with allergens from the "bubble bath" tests. Like Leodus Jones, Anthony has developed new metaphors to describe how his body schema has changed. During one of the more dangerous episodes, Anthony's body "swelled like an elephant's" and he had to be taken to the emergency room.[146] The nurses there peeled inches of swollen flesh from his feet and hands as he lay unconscious from the pain. On several occasions his "fingernails grew so hard and thick [he] had to use a wood saw to file them."[147]

Former subjects also spoke metaphorically when describing how their experience with Kligman and the doctors from the University of Pennsylvania had caused them to lose faith in the medical profession as a whole.[148] Although he sought medical care for his recurring skin disorders only when pressured by family and friends, Yusef Anthony finally decided he had had enough. In an interview with Allen Hornblum, he declared, "I said the hell with all those doctors I'd been seeing over the years. They weren't doing anything for me. The new ones I was seeing had no idea what I had or how to treat me, and the ones from Holmesburg were vampires and Frankensteins."[149] As mentioned above, investigators were uninterested in aftercare for surgery or in monitoring subjects

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[145] Annette John-Hall "Human Research: Anger, No Apologies," *Philadelphia Inquirer* (October 26, 2007).

[146] Ibid.

[147] Ibid.

[148] For a history of the how and atmosphere of mistrust has grown between black American and physicians see Vanessa Northington Gamble, "A Legacy of Distrust: African Americans and Medical Research," *American Journal of Preventive Medicine* 9 (1993) supp: 35-38; Vanessa Northington Gamble, "Under the Shadow of Tuskegee: African Americans and Health Care," *American Journal of Public Health*, 87, no.11 (1997): 4-9; and Harriet A. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present.* (New York: Doubleday, 2006).

[149] Hornblum, "Sentenced to Science," 185.

after they have been dismissed from a trial. After they had proved their usefulness, or at least proven that they were of no further use, Anthony and others like him were simply discarded, left in the field to decay. This callous disregard for human life earned the Kligman the "Joseph Mengele Award" for "inhuman actions above and beyond the call of duty."[150] The choice of blood-sucking monsters and mad scientists to describe Kligman and his ilk reveals how Anthony felt being treated as an object of the clinical gaze. Vampires like Kligman drained him and his fellow prisoners of their vitality and left them with scars to remind them of their experience. Frankenstein is a particularly apt metaphor as he stands as an example of how some quests for knowledge straddle the boundary between what is accepted because it is known and what is feared because it is unknown or poorly understood. According to the character of Frankenstein in Mary Shelley's novel of the same name, "the world to me was a secret, which I desired to discover."[151] For Kligman, this secret could only be discovered by treating other human beings as crops to be harvested. Though the cost to the subjects was horrific, part of the lasting damage that was done was inflicted on the medical profession.

Until his death in 2010, Albert Kligman refused to acknowledge that what he did was in any way problematic. Throughout his career he continued to be lauded by his colleagues who, for the most part, also seemed blind to his transgressions. The fact that he continued to be not only accepted but also celebrated by his peers shows how persuasive the rhetoric of reductionism is as expressed through the agricultural metaphor. Use of this metaphor to inform investigators' moral vision blinds them to the social and

[150] Hornblum, "Sentenced to Science," 193. This was an "award" that Anthony and others unsuccessfully tried to give Kligman at a dinner held in his honor at the University of Pennsylvania. See Annette John-Hall "Human Research: Anger, No Apologies," *Philadelphia Inquirer* (October 26, 2007).

[151] Mary Shelley, *Frankenstein; or, the Modern Prometheus (1818)* (New York, NY: Simon and Schuster, 2009), 24.

ethical values that their work undermines. According to published interviews with Kligman, even after Allen Hornblum's damning account of his activities was published he "repeatedly said that the research was within the accepted norms of the time and that no prisoner suffered long-term harm, as far as he knew."[152] Of course, these comments are patently false. He was sued on several occasions by prisoners who claimed that they suffered long-term harm due to participation in his experiments.

For example, in the case of Jerome Roach v. Albert Kligman, et al. the plaintiff was advised by one of the Ivy Research defendants that the experiment required him to take a "temperature pill" and that he would suffer no adverse effects.[153] After four days of participation, however, Roach developed various symptoms of physical illness including sore throat, sore joints, fever, nausea, and sores and rashes. The complaint alleges further that Roach was improperly treated for these symptoms by the prison doctor who prescribed penicillin without knowing or inquiring whether Roach was participating in an experiment. After a few weeks, Roach's condition grew serious enough for the defendants to arrange his transfer to Philadelphia General Hospital where he remained for several weeks. At the hospital, Roach was informed that his illness resulted from the experiment, that he had been given pills different from those described to him when he consented to the experiment, and that he had permanent liver damage. His claim that his civil rights had been violated by conduct of prison officials was rejected and his case was dismissed after being settled out of court with Kligman and Ivy Research.

[152] Denise Gelle, "Dr. Albert M. Kligman, Dermatologist, Dies at 93" *New York Times* (February 23, 2010).

[153] Roach v. Kligman et al., 412 F. Supp. 521, United States District Court, Eastern District of Pennsylvania (April 30, 1976).

As concerns Kligman's claims regarding the accepted norms of the time, these were laid out very clearly in the Nuremberg Code and the Declaration of Helsinki, which were both violated many times over in the course of Kligman's research. In fact, it is widely acknowledged that the current federal regulations were adopted partly in response to the violations of human dignity that occurred at sites like Holmesburg Prison. Even more damning is the fact that Kligman truly thought that the norms he was subscribing to would have permitted this kind of treatment. What is more frightening is that following the Holmesburg experiments, Kligman was actually placed on the medical ethics committee at the University of Pennsylvania! Even though he occupied this role and was clearly exposed to the moral insights provided by his colleagues after his own participation in blatantly unethical experiments, he still maintained the view that "shutting the prison experiments down was a big mistake … I'm on the medical ethics committee at Penn and I still don't see there having been anything wrong with what we were doing."[154] Sadly, the degeneration of moral authority that Kligman's case brings to light shows the limits of the power of rules and regulations to constrain the violations of human dignity that may arise as a result of a culture that embraces the agricultural metaphor. It is clear that this metaphorical understanding of the body of the Other was deeply engrained in Kligman's moral vision.

Kligman admits that his sense of power over the inmates in his studies made him think of himself as a Machiavellian character.[155] In his use of rhetoric, he very much resembles Machiavelli. Like Machiavelli, he used his most corrupting influence, access to money and drugs, to manipulate others for his own benefit. If one considers

[154] Ian Urbina, "Panel Suggests Using Inmates in Drug Trials" *New York Times* (August 13, 2006).

[155] Hornblum, 39.

Machiavelli's *The Prince* as part of the canon of the rhetors of reductionism, it may be seen as an instruction manual on how to maintain dominion over oneself and others. It poses a significant threat to the tradition of using rhetoric for morally praiseworthy ends. Most importantly, Machiavelli notes the instrumental relationship between force and persuasion. In his view, "men must either be caressed or else annihilated."[156] In other words, there are no half measures to be taken when one's power over a vulnerable population is at stake. Persuasion may work initially, but it is difficult to keep those who have been persuaded in that state.[157] When ruling either by law or force, it is "necessary to know well how to use both the beast and the man."[158] Kligman used both his knowledge of prisoners' need for money as a means for rising above the bestial power struggle of prison life and his ability to convince them that they were redeeming themselves in order to manipulate them. About his subjects he claims, "many of the prisoners, for the first time in their lives, find themselves in the role of important human beings."[159] Kligman, of course, assumes that these men are only important insofar as they are used by others as means to an end. His Machiavellian manipulation of prisoners was not the only way in which he disrespected prisoner-subjects.

Through its reduction of persons to mere commodities, the agricultural metaphor enables the kind of crude utilitarianism often lamented by bioethicists who have reviewed the case history of similarly minded investigators. In this view, a few prisoners trade their bodies for access to pleasures that satisfy their preferences while the preferences of other bodies for life and health are satisfied as well. It seems like a winning solution to a

[156] Niccolo Machiavelli, *The Prince (1532)*, trans. Luigi Ricci (London, UK: Oxford University Press, 1928), 8.
[157] Ibid., 22.
[158] Ibid., 69.
[159] Hornblum, 39.

difficult ethical problem. In fact, Kligman himself expressed confidence that paying prisoners to participate in research was improving their quality of life.[160] Kligman and others like him saw compensation as a form of respect, but in truth it simply perpetuated the system of oppression and limited possibilities that the modern philosophy of imprisonment as redemptive rehabilitation has engendered. Investigators were able to soothe their consciences by claiming that prisoners were not only fairly compensated, but also were "paying back a debt to society in a socially conscionable way."[161] One could argue that it is hardly conscionable to think that prisoners should literally give of their flesh to pay back any "debt" owed to society. Indeed flesh trading via the "supermarkets of investigatory opportunity" simply places a market value on a person's life.[162]

During the Holmesburg prison experiments, prisoners were paid a pittance to allow investigators to harvest portions of their bodies so that medical knowledge might be advanced. That their bodies were of value only insofar as they could be exchanged for cash was a surprisingly easy sale to many prisoners—though there were many who objected to the experiments for religious and other personal reasons. For example, converts to the Nation of Islam rejected offers to participate in these trials as they were seen as expansions of the white man's project of domination. Black prisoners were targeted by members of this congregation and persuaded to cease participating, often through coercive measures. For prisoners, whose ability to earn a living wage is severely limited, the money offered by Kligman opened up possibilities of living a more decent

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[160] A. Bernard Ackerman, "Holmesburg Prison, Philadelphia, September 1966- June 1967: Acknowledgment of Error and Regret," *Dermatopathology: Practical and Conceptual* 6, no.3 (July-September 2000): 214.

[161] Ibid.

[162] Allen Hornblum, "They Were Cheap and Available: Prisoners as Research Subjects in Twentieth Century America," *BMJ* 315, no. 7120 (November 29, 1997): 1440.

life, of being able to control some parts of their lives behind bars. As Yusef Anthony put it you "really needed money to be independent in there."[163] The power relations within prison placed Anthony and others like him in a complicated web of instrumentality in which prisoners saw each other as objects that could be manipulated and taken advantage of. At the center of the web were a variety of spiders: sexual predators, sadistic guards, gangs, murderers, rapists, and conmen. The University of Pennsylvania studies offered these flies a way to disentangle themselves from this web, but for a price.

At the edge of the web, Kligman and his associates offered a brief window of freedom from the drudgery of prison life, a chance to get high on some of the interventions being tested, and small sums of money that could be used to purchase goods at the commissary. In exchange, as Kligman himself put it, "all we did … is offer them money for a little piece of their skin."[164] This trading of commodities did not go without resistance on the part of other physicians working in the hospital. One of the psychiatrists who was not affiliated with the experiments remarked in an interview, "It was dreadful, [basically selling] flesh for a sum of money."[165] He referred to Kligman's acts and frame of mind as indicative of the "pound of flesh syndrome" born out of a medico-industrial relationship that commodifies the bodies of others.[166] Unfortunately, this pound of flesh syndrome seemed not to be contained within the walls of Holmesburg.

At about the same time as Kligman and his staff were treating the bodies of Holmesburg's prison population as agricultural commodities, Dr. Austin R. Stough was busy doing the same to prisoners in Alabama, Arkansas, and Oklahoma. Stough had

[163] Hornblum, "Sentenced to Science" 68.
[164] Ibid., 70.
[165] Ibid., 66.
[166] Ibid.

devised a method for "selling blood plasma extracted from prisoners."[167] Through a process known as plasmapheresis, blood plasma was separated from whole blood and the remaining blood products were reinjected into the subject. Stough founded a company called PlasmaCare to invest in the technology necessary to procure, store, and sell plasma to pharmaceutical companies.[168] Through this company he managed what essentially amounted to blood farms in three states. In Hornblum's phrase he "farmed the fertile fields of willing test subjects for several decades."[169] However, his activities eventually came to light once prisoners started dying of hepatitis, likely caused by his careless and infrequent monitoring of the transfusion process.

Federal and state investigators accused him of sloppy methodology, lax controls regarding adherence to the various protocols he was testing, and failing to report adverse reactions. Visitors from the various pharmaceutical companies that purchased his products noted contamination of Stough's equipment, but did not end their business arrangements with him. Although his plasma operations were all eventually suspended or turned over to a third party, he was still allowed to continue testing drugs on prisoners.

Stough's case highlights some of the ethical problems that can arise when bodies are treated as commodities. In this case, blood was seen as a cash crop, a commodity to be sold to others without benefitting the prisoners. Prisoners were subject to mismatches in type and suffered from horrendous side effects from mistakes made by investigators and assistants. One such hapless prisoner was Tommy Lee Knott, an inmate in Oklahoma with O positive blood who was injected with A negative, which led to severe organ

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[167] Jessica Mitford, *Kind and Usual Punishment: The Prison Business.* (New York, NY: Alfred A. Knopf, 1973), 154.

[168] PlasmaCare website. http://www.plasmacare.com/pages/about

[169] Hornblum, 97.

damage.[170] Knott was actually one of the lucky ones. Unlike him, another prisoner at the ironically named Cummins Farm in Arkansas died after receiving a whooping cough injection. [171] Stough's willful neglect of his subjects' health and his lack of concern for their well-being or for sharing his profits with them after draining them of their blood is eerily reminiscent of Kligman's activities at Holmesburg. Furthermore, his use of blood as a commodity adds an air of vampirism to his activities that would also be at home in Holmesburg. Like a greedy farmer, he planted roses and harvested their flowers, only to leave the stalk and roots to wither in the sun.

This metaphor of the body as an agricultural commodity continues to be employed in the way that bodies are treated by physicians looking to patent cell lines and profit off of the resources of patients' and subjects' bodies. The well-known case of John Moore, a businessman with hairy cell leukemia, whose cell line was patented by a physician at UCLA and a Swiss pharmaceutical company, illustrates how dehumanizing this way of treating persons can be. In response to the commodification of his body, Moore noted that his physicians "view me as a mine from which to extract biological material. I was harvested."[172] Note that he claims that *he* was harvested, not that his body was harvested. By using the body of the Other merely as a means for profit and scientific knowledge, the humanity of the Other is reduced to an economic commodity.

The dissenting opinions in the Moore ruling are instructive in the sense that they open up questions about the usefulness of the idea of the body as a commodity. Justice Mosk, dissenting from the majority opinion that denied Moore's property rights, argued

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[170] Walter Rugaber, "Prison Drug and Plasma Projects Leave Fatal Trail: Trail of Injury and Death in Prisons Follows Doctor's Drug and Plasma Programs" *New York Times* (July 29, 1969).

[171] Ibid.

[172] Andrews and Nelkin, 1.

that property rights do inhere in the biological materials of human bodies and that control over the use of these materials is integral to the protection of human dignity.[173] Justice Arabian noted that this discussion of property rights is inappropriate in that it asks the justices to "commingle the sacred with the profane."[174] He rejected the argument that human bodies should be commodified and that the legal system should adjudicate disputes regarding their market value.

Richard Gold, in his discussion of property rights, hits on a theme that is applicable to our discussion on ownership and subjects' bodies. In a discussion of the natural beauty and resources of the ocean, he mentions that assigning property rights to individuals who wish to use an object in a particular way encourages this instrumental usage while declining to assign property rights to those who value the ocean in a noninstrumental way (i.e., as an object of beauty) discourages this view.[175] By signing a consent form, subjects in a sense grant temporary property rights to the investigator, limited only by the duration and nature of the protocol and subject to immediate termination for any reason or no reason at all. The consent form itself plays a vital role in establishing the right to consent, the right to ask for permission, and the right to temporarily lift social restrictions on trespassing across bodily boundaries. However, the consent form also reinforces the view that the human body is a piece of property and does not encourage the view, beyond the codification of consent as an expression of respect for persons, that the body has intrinsic value. Indeed, it codifies the view that the body is a commodity whose value should be determined by the market price.

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[173] Richard Gold, *Body Parts: Property Rights and the Ownership of Human Biological Materials* (Washington, DC: Georgetown University Press, 1996), 32.

[174] Ibid., 35.

[175] Ibid., 4.

In sum, Albert Kligman showed disrespect for subjects because he was not willing to take the time to run the tests properly, stay within his discipline, or hire the appropriate staff. He oversaw medical tests for which he was not qualified including radiation studies and psychopharmaceutical studies that were not properly staffed. The FDA accused him of falsifying data and of running hundreds of trials, many at the same time. He also was accused of using subjects for multiple trials simultaneously, thus confounding the results. He also did not report some adverse events, ended studies prematurely, and destroyed records. For these breaches of scientific integrity, the FDA suspended him for one month. As fellow dermatologist Bernard Ackerman put it, "To designate what was done there as scientific research makes a mockery of both science and research; it was a big business in the guise of research and in which the factory was a county prison, the patron was an Ivy League university, the customers were pharmaceutical and cosmetic companies, as well as the CIA and the US military, and the merchandise was skin of prisoners, who, without informed consent, were used mostly for the object of making money."[176]

As the consequences of the Holmesburg prison experiments began to surface in revelations in the press regarding the mental and physical pain and suffering of prisoners and their growing distrust of the medical profession, some of Kligman's colleagues began to turn against him. However, there were those who continued to defend him. One such article expressed outrage at the accusations and claims that the "matter of the ethics of conducting research on vulnerable populations was settled some 25 years ago."[177] In his letter to the editor, Richard Tannen notes that the use of prisoners was a "commonly

[176] Ackerman, 215.

[177] Richard L Tannen, "The Ethical Issues of the Holmesburg Studies Have Been Addressed," *Dermatopathology: Practical and Conceptual* 6, no.3 (July-September 2000), 222.

accepted practice."[178] Tannen expressed his satisfaction with the system of IRB oversight and the federal regulations, but he misses the point about how investigators must be committed to showing respect for persons, not using them as mere objects, which was one of bioethicists' primary concern with the Holmesburg prison experiments. In a scathing response to Tannen, Wolfgang Weyers responded that "both Nazi physicians and physicians of the University of Pennsylvania treated their test subjects as raw material for scientific studies and as a vehicle for academic advancement, rather than with respect as human beings."[179] As Weyers's comments imply, how respect for the most vulnerable is shown is an indication of a society's moral standing. How those most needing respect and most poorly positioned to demand it are treated is an indication of how persons and bodies are valued by the scientific enterprise.

Maurice Pappworth, whose history of human subjects research stands as one of the canonical texts in the field, declared that "no doctor … has the right to choose martyrs for science or for the general good."[180] The notion of prisoners and soldiers as martyrs for science opens up interesting questions about how some subjects may willingly invite investigators into the sacred wilderness of their body. However, this invitation requires that investigators also recognize that violations of the sanctity of the body will not be tolerated. In order for subjects and investigators to be truly "companions in medical science and adventure" both parties must make their possibilities the possibilities of the

[178] Tannen, 222.

[179] Wolfgang Weyers, "Failure to Appreciate the Validity of Accusations About Violations of Ethics," *Dermatopathology: Practical and Conceptual* 6, no.3 (July-September 2000), 226.

[180] Hornblum, xviii.

Other.[181] Choosing a metaphor that captures all of these possibilities is a necessary first step.

[181] Mitford, 161.

Chapter 3: Rediscovering the Body as a Sacred "America"

As the previous chapter demonstrated, in order to generate a fuller conception of respect for persons, investigators must be willing to broaden their moral vision. Part of this process involves abandoning completely or at least partially the mechanical, industrial, and agricultural metaphors of the body. The reductive power of the industrial and agricultural metaphors seems too great to allow them to continue to drive the research enterprise. From a moral standpoint, they threaten the integrity and inherent dignity of human beings by conceptualizing them as mere objects of knowledge production or as mere material commodities, respectively. Though the mechanical and industrial metaphors do serve some epistemic functions, they must be tempered with a broader moral vision that not only values the instrumental function of bodies in the production of knowledge but also recognizes the inherent worth of human beings as body-subjects. The agricultural metaphor, on the other hand, is both epistemically useless and morally pernicious. It should be abandoned completely. Fortunately, there are other metaphors that can take its place. In this chapter, I will describe and analyze alternative metaphors that will broaden the moral vision of investigators and provide a means for generating a more capacious sense of respect for persons.

These alternative metaphors, which I will call the temple metaphor and the America metaphor, have roots in foundational images that have developed over the course of many centuries as humans have struggled to find their place in the cosmos. Both have been used to illuminate certain truths about the body and its dual nature as both sacred and profane. Each metaphor uncovers the inherent worth of the body by

speaking to the sacredness of the body as the nexus of lived experience. Within the lived experience, bodies recede from view yet they remain essential to the reception and absorption of life experiences. By seeing the body as an integrated organic totality that is deeply embedded within the world, investigators will be more receptive to its needs and more respectful of the person as a whole. Reintegrating the temple and America metaphors into the consciousness of the investigator is crucial for the moral development of medical research as a practice.

From its roots in St. Paul's letter to the Corinthians, the metaphor of the body as temple has traditionally had strong roots in Christian theology. In this section, I will consider this metaphor as the basis for holistic ideas about the body as an organic totality. From these theological roots, I consider the secular equivalent of the body as a sacred space. Furthermore, I propose an alternative reading of the body that encourages the integration of the carnal and the spiritual within the architectural conceit of the temple. Although it would seem at first glance that this metaphor would preclude any scientific endeavor that proposed to invade the sacred space of the body, the history of medical humanism shows that this is not necessarily the case. For example, during the Renaissance, Andreas Vesalius used his understanding of religious symbolism to frame his search for anatomical knowledge as a religious quest to understand God's handiwork.[1] The recovery of the sacred body and the theological and ethical constraints imposed by the scriptural arguments for stewardship of the body that accompany the temple metaphor may not be incompatible with the pursuit of medical research as a social good.

[1] Andreas Vesalius, *De Humani Corporis Fabrica Libri Septem.* (Basel, Switzerland: Joannis Oporini, 1543). See also Vivian Nutton, "Introduction" http://vesalius.northwestern.edu/books/FA.

UNCOVERING THE SACRED BODY

As an alternative to the mechanical and industrial metaphors mentioned in chapter 2, the metaphor of the body as temple or sanctuary fundamentally shifts and expands the moral vision of the investigator. Instead of being seen as merely a profane object whose essence is reducible to the laws of mechanics and hydrodynamics, the lived body as temple is revealed to be a sacred and vital presence within the world. The image that grounds this metaphor is a transference of divine wisdom and care to a material body that inhabits a material world. As an architectural conceit, the temple metaphor evokes a divine builder whose design binds the spiritual to the material through flesh. It describes the lived body as carnal and mischievous, but also as sacred and pure. Such a metaphor allows for the ambiguity of the dichotomous relationship between subjectivity and objectivity to coexist within a single human frame. While the machine metaphor renders profane what was once sacred, the temple metaphor uncovers the sacredness of the body.

To frame this inquiry into the source and the power of the temple metaphor, I will begin with a brief analysis of the scriptural source for this image. In his letter to the congregation at Corinth, St. Paul calls them to reflect on their embodiment, saying "*ἢ οὐκ οἴδατε ὅτι τὸ* ***σῶμα*** *ὑμῶν ναὸς τοῦ ἐν ὑμῖν ἁγίου Πνεύματός ἐστιν, οὗ ἔχετε ἀπὸ Θεοῦ, καὶ οὐκ ἐστὲ ἑαυτῶν*? Or do you not know that your body is a temple of the Holy Spirit who is in you, whom you have from God, and that you are not your own?" [2] This passage and other similar reflections scattered throughout Pauline theology serve as central foci for theological debates about the holism and sacredness of the body. Scholars have theorized that Paul chose the term *soma* (*σῶμα*) to describe the body in this verse instead of another

[2] 1 Corinthians 6:19. Emphasis added. Greek Orthodox Church (Greek) and New American Standard Bible (English). http://scripturetext.com/1_corinthians/6-19.htm

Greek term, *sarx* (*σάρξ*), because he was attuned to the subtle differences in meaning between the two terms.[3]

In other passages describing the body, Paul uses the term *sarx*, meaning "flesh." In contrast to *soma*, *sarx* "stand[s] for anything external and visible, as opposed to what is internal and spiritual."[4] Paul uses it to describe human beings as flesh, which points to their weakness, subservience, powerlessness, fallibility, and mortality. Though it has more pejorative connotations than *soma*, *sarx* can also point to humanity's "worldliness, in the solidarity of earthly existence."[5] This solidarity is a product of the fragility of the human condition as embodied beings in the world, with all of the vulnerabilities that this worldliness implies. The notion of *soma* anticipates some of these deeper connections between body, person, and world.

Soma is often taken to mean not merely the body but the person in general.[6] This usage of the term is consistent with the early Judeo-Christian belief that "man does not *have* a body, he *is* a body. He is flesh-animated-by-soul, the whole conceived as a psycho-physical unity: 'The body is the soul in its outward form.'"[7] This view of personhood and embodiment is the essence of theological holism, which may be contrasted with Plato's theory of the soul as well as Cartesian dualism. Theological holism has important implications for the notion of respect for persons. For if the person is the body then showing respect for the body must be a necessary condition for showing respect for the person. Bodies unite persons with others through their sacredness and organic totality. To recognize the sacredness of the Other, one must first read the body of

[3] See John A.T. Robinson, *The Body: A Study in Pauline Theology* (Philadelphia, PA: Westminster Press, 1952) and Dale Martin, *The Corinthian Body* (New Haven, CT: Yale University Press, 1995).

[4] Ibid., 18.

[5] Ibid., 21.

[6] J.A. Ziesler, "ΣΩMA in the Septugint," *Novum Testamentum* 25, no. 2 (Apr., 1983): 133.

[7] Robinson, 14.

the Other as "a sign or image of God, the 'analogical verification' of the divine."[8] Bodies serve as reminders of the divine Incarnation, of the Word becoming flesh. As a vessel of the Holy Spirit, the body in its engagement with the world and with other bodies reflects the sacredness of divine love. In this sense of communion with others the idea of *soma* reflects the essence of embodiment, which binds persons to one another. It describes the body as "that which joins all people, irrespective of individual differences, in life's bundle together."[9] Not only is the individual body a sacred space in which the holy mysteries of life take refuge, but each body is also a part of the wider community of embodied beings. "Corinthian" bodies, so to speak, are not simply self-contained totalities, but extend into their environment.

In general, Western religious traditions "affirm the ontological reality of the body as well as its intrinsic moral goodness, in contrast to the instrumental value embedded in Cartesian and materialist thought."[10] This ontological reality is a product of the organic totality of the body. The temple or sanctuary suggested by the Corinthian body described in Paul's letter is not unfinished, but a complete and perfect dwelling place of the sacred. It is the body as a whole that matters. In Roman Catholic interpretations of embodiment, the body is "greater than the sum of its parts."[11] In contrast to metaphors inspired by Cartesian materialism, metaphors that describe body-subjects cast them as emergent phenomena, where their emergence signals their holiness and their mystical qualities.

Yet, as the theologian and philosopher Courtney Campbell notes, the "body as temple" metaphor can also be read as an example of theological dualism, analogous to the Platonic metaphor of the body as a prison for the soul. This reading arises from the

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[8] Courtney S. Campbell, "Marks of the Body: Embodiment and Diminishment" in *Embodiment, Morality, and Medicine* ed. Margaret A Farley (Dordrecht, Netherlands: Kluwer Academic Publishers, 1995), 171.

[9] Robinson, 29.

[10] Courtney S. Campbell, "Religion and the Body in Medical Research," *Kennedy Institute of Ethics Journal* 8, no.3 (September 1998): 290.

[11] Ibid., 277.

contrast that arises when considering the body as a material entity that houses the Holy Spirit, which is immaterial. Objections to the theological interest in the physicality of the body often arise from its frailty and mortality as flesh. While the temple of the body itself may be a physical structure, it also is constantly in a state of flux as it is worn down by time and the imprints of visitors. It too decays and is repaired, but eventually will collapse and, following Christian theology, be raised again. Belief in the resurrection of the flesh at the end of days suggests a wide area of ambivalence regarding its supposed inferiority to the spirit, which is itself based on a dualistic understanding of embodiment. However, Campbell argues for an alternative interpretation, similar to Merleau-Ponty's understanding of the world as flesh, that sees the temple metaphor as an indication that the body is a "dynamic locus and medium of action, religious community, and revelation of knowledge."[12] Instead of neatly separating body and spirit, Campbell describes the body as a locus for the integration of mind, spirit, energy, and material. Within the experience of the body as lived, this integration is seamless. In this holistic sense, bodies as temples do not merely house religious relics. Instead, they serve as meeting places for the community of worshippers to connect with each other along a common purpose. All bodies share the power to draw other bodies into their circle of influence. In everyday experience, the holiness of the body of the Other may be offered as a gateway to spiritual knowledge and earthly communion. This is an offer to transcend the limits of the individual body and to participate "in an order other than the purely corporeal: holy, sacramental and mystical, and also personal, loved and loving."[13] To arrive at such transcendence is to embrace the organic totality, holism, emergence, and sacredness of the body.

[12] Campbell, "Marks of the Body," 17.

[13] Anthony Synnott, "Tomb, Temple, Machine and Self: The Social Construction of the Body," *The British Journal of Sociology* 43, no. 1 (March 1992): 85.

According to Pauline theology, the body as a temple for the Holy Spirit is clearly a sacred space. In theology, the sacred is often defined by its opposite, the profane. Ontologically speaking, the sacred is ontically prior to the profane, since the former is the ground of all reality while the latter merely participates in being. In Mircea Eliade's elegant phrase, "the sacred is saturated with *being*."[14] Conversely, the profane is always moving towards nonbeing. Since the essence of the lived experience is being-in-the-world, the body as one's grounding in the world is the root of the sacred. In this sense, revelation of the body's essence is a hierophany. Opening the inner spaces of the body, whether through discourse, artistic expression, or through physical means is to tread on "'sacred space' or what Mircea Eliade refers to as a *hierophany*, a medium for the manifestation of the sacred in human experience."[15] The body revealed is familiar, yet foreign. For example, the experience of seeing one's body reflected in a mirror or on a medical monitor is an uncanny experience. Such an experience may cause one to reexamine how one sees the world, compared with how he may be experienced by the Other. Visual schemas which attempt to synthesize these two views, the internal and the external, are sacred visions in that they reacquaint oneself with the "wholly other."[16]

From a scientific viewpoint, the body is wholly profane. It is a neutral space that merely serves as a "source of knowledge of physical development, aging, and disease."[17] Investigators do not recognize that when they approach the body of the research subject, they are approaching the threshold of the sacred. In general, they tend to be blind to the signs that indicate the presence of the divine. Eliade describes the threshold between the temple and the outside world as a boundary between "two modes of being."[18]

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[14] Mircea Eliade, *The Sacred and the Profane* (Orlando, FL: Harcourt Brace and Company, 1959), 12.

[15] Courtney S. Campbell, "Body, Self and the Property Paradigm," *Hastings Center Report* 22, no.5 (September- October 1992): 35.

[16] Eliade, 9.

[17] E. Richard Gold. *Body Parts: Property Rights and the Ownership of Human Biological Materials*. (Washington, DC: Georgetown University Press, 1996), 148.

[18] Eliade, 25.

Approaching the body of the research subject and seeking permission to cross the threshold of the skin should be a sign that something momentous is occurring. For the religious man the signs are everywhere. From the touch of the hand and the warmth of the breath to the folding of proteins, the body speaks the signs of the Divine Architect. In Campbell's view, these signs mark the "break between sacred and profane. This distinction of sacrality gives the body the attribute of otherness that demands recognition and respect from persons."[19] This "break" is actually a liminal space that the body inhabits between these categories. In a sense it is both sacred and profane, but neither entirely corrupted nor entirely pure. The "otherness" Campbell speaks of is of a piece with the divine Otherness that makes the body a holy relic.

As an example of the confluence of the sacred and profane within medical research, the history of dissection offers both religious and scientific views of the body, often within the same texts. For example, in the sixteenth century, the well-known anatomist and physician Andreas Vesalius's quest was couched in religious language. In his letter to Charles the Fifth, wherein he offers his book *De Humani Corporis Fabrica* (1542) as a tribute to the emperor's interest in science, Vesalius outlines his project as "research in which we recognize the body and the spirit, as well as a certain divinity that issues from a harmony of the two, and finally our own selves (which is the true study of mankind)."[20] In this one sentence he collapses the dualism of the body and the spirit into a holistic view of the body and spirit as existing harmoniously within the body from which the self emerges. Furthermore, his images follow the contemporary convention of combining scientific and religious images within anatomical texts. Jonathan Sawday points to the *gravida* images of the sixteenth century as an example of this tradition.[21]

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[19] Campbell, "Marks of the Body," 172.

[20] Andreas Vesalius, "To the Divine Charles V, the Mightiest and Most Unvanquished Emperor: Andreas Vesalius' Preface to his books On the Fabric of the Human Body (1542)," trans. Daniel Garrison and Malcolm Hast. http://vesalius.northwestern.edu/books/FA.a.html .

[21] Sawday, 103-105.

Although the women in these images, such as the one below drawn by Johannes de Kethem in *Fasiculo de Medicina* (1490), are splayed open with the fetus they are carrying clearly visible, the index fingers on their right hands are raised up to the heavens, signifying a divine link between birth and dissection (Figure 2). In the course of both birth and dissection, spaces are opened up that once were hidden. The placidity of the face and the elevation of the eyes suggest a Madonna-like figure who has given of her body so that the dissector may explore the dual nature of the Christ-child. Exploring each space provides either the midwife/obstetrician or the dissector/surgeon with access to a boon that is both sacred and profane.

Figure 2: Johannes de Kethem, "Disease Woman" *Fasiculo de Medicina*, 1490. Image Courtesy of the Blocker History of Medicine Collection, Moody Medical Library, The University of Texas Medical Branch, Galveston, TX.

The spaces in which bodies were opened up to the new regime of ocular empiricism in anatomical study also shared this duality. In fact, some dissections took place in churches. One can imagine the curious juxtaposition of the altar which held the sacramental relics standing mere meters away from the splayed and spliced body of an executed criminal. This juxtaposition creates an interesting clash of hagiographical references. Of course, to the anatomist and his contemporaries, the bodies of criminals were not sanctified but already expelled from the sacred body of Christ. Yet, they served as martyrs to medical research. Like the saints adorning the walls of the church, the gift of their bodies (not freely given on the part of the criminals, of course) "dramatically reveal us to ourselves, made in God's image, complex, holy, vulnerable."[22] Though their bodies had been tainted by sin, their inner spaces still displayed the craftsmanship of the Divine Architect. Historian Mary G. Winkler describes dissection as a kind of ritual initiated by a procession led by the anatomical faculty that concluded with the dissector entering the room like a priest delivering himself to the faithful.[23] She also cites anatomical texts that summon readers to the spaces where "God lies hid."[24] The body as temple was unveiled in the temple itself. Within this space the body of the condemned criminal became the epitome of the earthly sacrifice of Christ and other martyrs.

Vesalius's sense of decorum in visual rhetoric allowed him to place his investigations within the tradition of pious investigations of God's handiwork. The frontispiece "stressed the religious nature of the act ... by depicting Vesalius pointing upwards to heaven, thereby invoking the purposeful divine order of creation."[25] In addition, cherubim and seraphim hold the title of his book between them. Following the ancient tradition of exploring the divine teleology of the body, anatomists hoped to reveal

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[22] Mary G. Winkler, "The Anatomical Theatre," *Literature and Medicine* 12, no. 1 (Spring 1993): 69.

[23] Ibid., 67.

[24] Ibid., 68.

[25] Vivian Nutton, "Introduction" http://vesalius.northwestern.edu/books/FA

the "technical genius of the Creator who had so perfectly fitted form to function."[26] Thus, Galenic anatomy could be reconciled with the teachings of the Church regarding creation and the notion of the body as a sacred image of God. The orderliness of the body as a collection of interdependent systems reflected the orderliness of the incarnation, for in Greek *logos* can also mean "order." The Word incarnated in the image of God meant that the body itself reflected God's plan for mankind. This hierophany was revealed in the public discourse, both religious and secular, that applied themes of the divine architecture to the study of the body by nonphysicians.

In the minds of public scholars and anatomists, anatomical images were organized as architectural conceits that "reinforced the scriptural idea of the body as the 'temple' of the incarnation."[27] Vesalius examined the skeleton first in *De Fabrica* because he recognized that it made more sense to begin with the architectural foundation of the body. As the figures below show, drawings of the circulatory system resemble scaffolding (Fig. 3). Although the frame of the bones is missing, the intimate network of crisscrossing veins and arteries are reminiscent of the electric wires and pipes that enable modern structures to function as habitations (Fig. 4). Vesalius himself invoked the architectural image of the body, noting in a letter to Parthenopeus that it was "not only noble and beautiful but profitable and essential to contemplate the ingenuity and workmanship of the Great Architect."[28]

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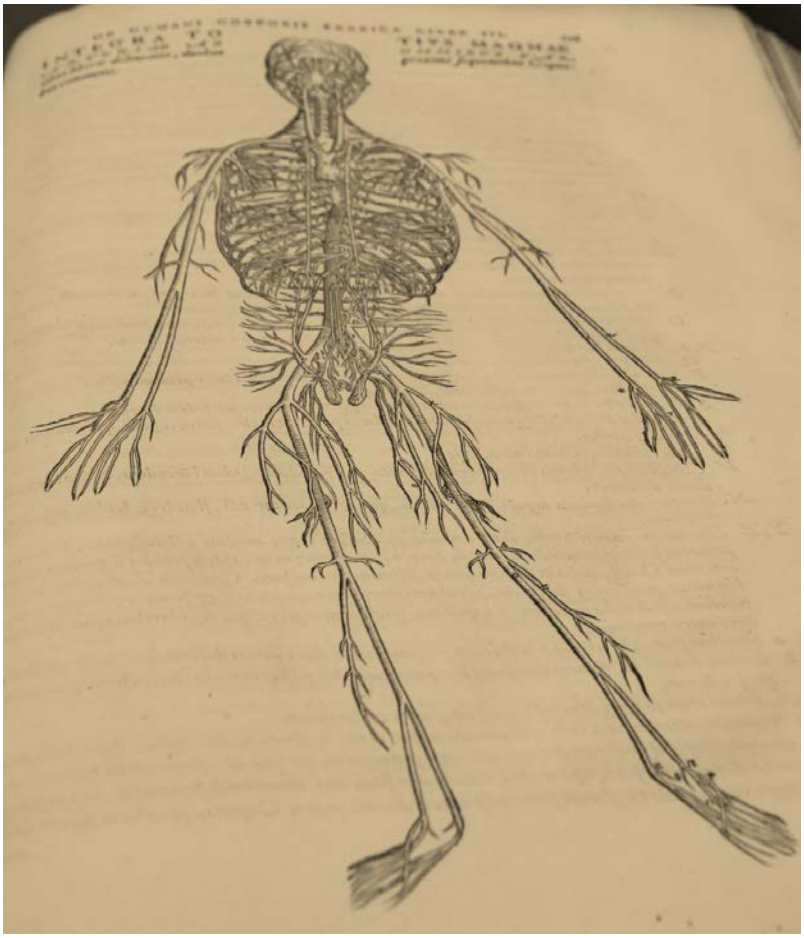
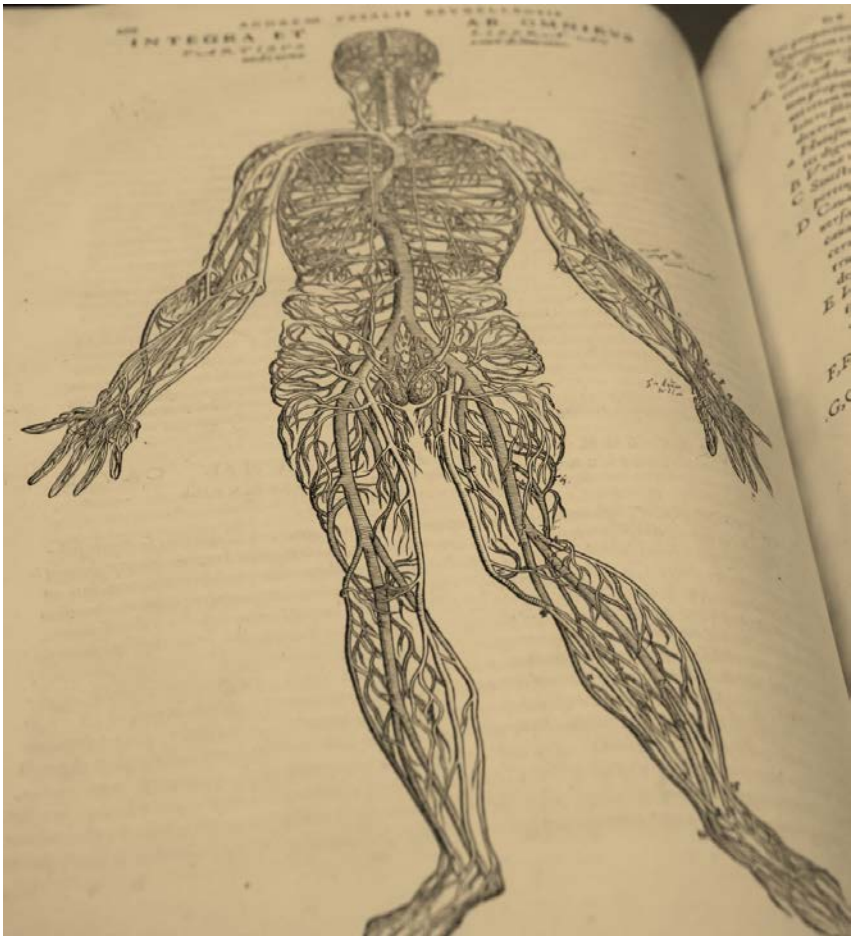
[26] Ibid.

[27] Sawday, 131.

[28] Dedication to Narcissus Parthenopeus in *Tabulae Anatomicae Sex* (1538). Quoted in John Bertrand de Cusance Morant Saunders and Charles Donald O'Malley, *The Illustrations from the Works of Andreas Vesalius of Brussels: With Annotations and Translations, a Discussion of the Plates and Their Background, Authorship and Influence, and a Biographical Sketch of Vesalius* (Cleveland, OH: Dover Publications, 1973), 234.





Poets and priests were stunned at the intricacy of the human body. They compared it to a vast labyrinthine castle where one could easily get lost and disappear forever. In poet and priest John Donne's sermons he describes his search for the finite in the infinite thusly, "When I looke into the larders and cellars, and vaults, into the vessels of our body

for drink, for blood, for urine, they are pottles and gallons; when I look into the furnaces of our spirits, the ventricles of the heart and of the braine, they are not thimbles."[29]As a poet, Donne was captivated by the seeming vastness of the interior spaces of the body. In his romantic verses Donne often alludes to the infinite domain of space and heavenly bodies in his remarks on the body of his beloved and the longevity of his love. As priest, Donne recognized that "every particular man is himselfe *Templum spiritus sancti*, a Temple of the Holy Ghost."[30]

For some scientists and physicians, part of the divine plan involved not just finding humanity's place in the universe, but forcing nature to conform to the will of human beings. In this sense, the pursuit of anatomy, whether literally or figuratively, is a kind of cosmogony. Anatomists and investigators do not simply use the clinical gaze to discover worlds, but in the course of their exploration they make worlds. While the reality of the body as a physical substance may be assumed, the nature and form of it is discursively shaped. Although investigators in the twenty-first century and anatomists in the fifteenth and sixteenth centuries encountered essentially the same physical, fleshy substances formed in the same general proportions, their views of the body are radically different. For Eliade, making worlds, that is, the act of bringing cosmos to chaos is itself a sacred act.[31] It does not matter whether the world is physically constructed out of wood, stone, blood, sweat, and flesh or if it is discursively constructed. Each is an act of finding the *axis mundi* and making of it an *imago mundi*. For the metaphor of the body as temple of the Holy Spirit, the *axis mundi* is the body itself. The microcosm-macrocosm analogy has historical significance as the discursive and visual formulation of the body as *imago mundi*.

[29] Ibid., 19.
[30] Ibid., 126.
[31] Eliade, 30.

Although it is an analogy that has fallen out of favor, thanks in part to the Scientific Revolution of the seventeenth century and the work of Copernicus and Galileo, the idea of the micro-macrocosm shares many features with the temple metaphor. It expresses a kind of reverence for an architectural or engineering model of how cosmology shaped the development of natural philosophy and medicine, especially human anatomy and physiology. The analogy places the human form in correspondence with the "the greater form of the macrocosm."[32] In other words, man was seen as a smaller version of the organization of the universe. Through his capacity for reason, he was said to participate in the perfection of the universe as a world that is rationally ordered. Human bodies were expressions in "in miniature [of] the divine workmanship of God."[33] As a cosmological extension of the temple metaphor, the micro-macrocosm places man at the center of the universe, though he is also at its mercy. For the ancients who subscribed to the microcosmic metaphor, "the differentiation between inner and outer body was fluid and permeable."[34] This interpretation of the analogy shares some features of theological holism with the temple metaphor. In more modern terms, it is consonant with the idea of man as a biopsychosocial creature. Although the microcosm-macrocosm metaphor fell out of favor due to the growing influence and cultural authority of science, secular images of the body as sacred sanctuary have remained.

Centuries after the rise of the micro-macrocosm analogy fell out of favor, Walt Whitman elaborated on a more secular understanding of the sacredness of the body. After his experience as a nurse during the Civil War, Whitman emerged as a Romantic poet of the everyday.[35] It may seem surprising that someone who witnessed firsthand the war-torn bodies of countless young men would still see the body as sacred. Yet, in his poem

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[32] Sawday, 23.

[33] Ibid.

[34] Martin, 20.

[35] Martin Murray, "Traveling with the Wounded: Walt Whitman and Washington's Civil War Hospitals" *Washington History: Magazine of the Historical Society of Washington, D.C.* 8, no. 2 (1996-1997) 58-73, 92-93.

"Song of Myself," Whitman celebrates the sacredness of the body. In his earthy and unflinching way, Whitman declares:

> Divine am I inside and out, and I make holy whatever I touch or am touch'd from,
> The scent of those arm-pits aroma finer than prayer,
> This head more than churches, bibles, and all the creeds,[36]

The touch of holiness Whitman notes is an extension of his idealization of a kind of secular humanism that still manages to extol the sacredness of the body. Whitman reveals how the body itself, even its odors, fluids, and frailties, is more divine than the thoughts one lifts to heaven in prayer. Sacredness saturates the body more thoroughly than those spaces that are constructed to worship the divine. Throughout "Song of Myself" and indeed throughout *Leaves of Grass*, Whitman revels in the sensuality and the aesthetic beauty of the body. For him, "the man's body is sacred and the woman's body is sacred/ No matter who it is, it is sacred …"[37] In our embodiment we are all equally valuable and sacred. Coming on the heels of the Civil War, this is a truly brave statement to make.

Whitman draws on the legacy of this historical episode in observations he notes on watching a slave auction prior to the Civil War:

> Gentlemen look on this wonder,
> Whatever the bids of the bidders they cannot be high enough for it,
> For it the globe lay preparing quintillions of years without one animal or plant,
> For it the revolving cycles truly and steadily roll'd,[38]

From Whitman's verse, one can begin to piece together a secular argument for the sacredness of the body as temple. First, it is priceless. Though it is composed of parts that together constitute a person, no price can legitimately express the value of human life and the experience of embodiment. As Whitman suggests, the body is a product of forces that

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[36] Walt Whitman, "Song of Myself" in *Leaves of Grass (1892)* (New York, NY: Bantam Books, 1983).

[37] Whitman, "I Sing the Body Electric" in *Leaves of Grass (1892)*, 80.

[38] Ibid.

operate in geological time, not in New York minutes. As a manifestation of the evolutionary forces necessary to support individual human lives, the body is a testament to the wondrous power of nature. Second, each body is unique. Individual bodies, though carved from a general genetic template, carry with them the heritage of generations of human beings. They are monuments to the endurance of the human race, yet each possesses its own style and image. The uniqueness of each body-subject, together with the intrinsic value of its emergence as a complex organism, provides an argument for demanding respect and even reverence.

Awe and reverence for the body of the Other are part of the moral implications of the temple metaphor. Indeed, use of the temple metaphor implies that "the appropriate disposition may be more reverence and awe than respect."[39] To return to these facets of the temple metaphor as they emerge from contemplation of the Corinthian body, Paul's ambivalence regarding how the body should be treated is a highly debated aspect of Pauline theology. While some passages would seem to suggest that the body as flesh should be mastered, others suggest that this mastery is not a punishment but a way of purifying and honoring the body so that it might serve both the self and God.[40] The question remains whether Pauline theology would permit the body to be used for medical research or whether putting it to such use would defile it. More modern Christians have interpreted Paul's Corinthian body as one that demands that its stewards maintain it by adopting healthy habits of nutrition, exercise, and mental health. In so doing the sacredness of the body is protected. Offering one's body and one's health in service to other sacred beings seems to be consonant with many other parts of Christian theology. For example, theologian John A. T. Robinson claims that *soma* "stands for man in the solidarity of creation, as made for God." [41] This view implies a kind of stewardship of the

[39] Campbell, "Body, Self, and the Property Paradigm", 35.
[40] Synnott, 86.
[41] Robinson, 31.

body that is consonant with its status as a temple of the Holy Spirit.[42] Control over the body and its disposition is a responsibility often portrayed as "trusteeship" or "stewardship" from the Creator.[43] Responsible stewardship involves accountability for uses of the body and orientation of such uses toward the common good.[44] This orientation would seem to support the use of the body in medical research.

Under another interpretation of the stewardship model, using the body to test drugs that may harm it risks injury and desecration of the temple. Furthermore, doing so would seem to violate the purpose of the body in favor of its mere functionality as an instrument. It seems reasonable to think that doing so for money would conflict with Jesus's teachings about the cleansing of the temple. In the Book of Matthew, there is a story that concerns a rare instance of righteous indignation at the desecration of the temple by usurers. Charging exorbitant fees to parishioners for the right to make sacrifices to the Lord was enough to get the moneychangers expelled from the temple grounds. Matthew writes, "And Jesus went into the temple of God, and cast out all of them who sold and bought in the temple, and overthrew the tables of the moneychangers, and the seats of them that sold doves, And said unto them, It is written, My house shall be called the house of prayer; but ye have made it a den of thieves."[45] Taken metaphorically, the sacred body under the agricultural metaphor becomes a den of thieves. Metaphorical readings of the body and the scriptures that describe it seem to encourage a prohibition against selling one's body, for medical research or otherwise. Such a move would seem to cheapen the intrinsic value of the body, permitting access to it by those who are unworthy of its holiness.

Physicians have historically been granted admittance to the temple of the body because of their association with the arts and rituals of healing. The idea of the physician

[42] Robinson, 31.
[43] Campbell "Religion and the Body in Medical Research," 192.
[44] Ibid., 291.
[45] Matthew 21:12-13

as priest is amenable to the temple metaphor. However, when physicians don the lab coat, their admittance to the temple should undergo a more intense level of scrutiny. They are no longer priests, but detectives, interlopers from the outside who ask admittance not to worship and heal the broken body, but to examine it, test it, and use it as an instrument for other ends. They must prove their allegiance to the community of the body and show their reverence. To do so may require adopting the awe and reverence for the body that the physician as priest should show. Developing a metaphor that can persuade investigators to take the sacredness of the body seriously requires not simply a moral grounding but also an epistemic focus that can drive scientific innovation and imagination. The metaphor of the body as America invites investigators to consider the ambiguity of the body as both charted and uncharted territory.

DISCOVERING THE BODY AS AMERICA

Another alternative to the mechanical, industrial, and agricultural metaphors used to shape investigators' moral vision of the body is the image of the body as America. Jonathan Sawday in his book *The Body Emblazoned* shows how anatomists and poets during the early Renaissance used this metaphor to encapsulate a wide range of values and draw on a number of images. It is a complex notion that befits the intricate and multifaceted relationship that we have with our bodies. Sawday's usage of the term to compare Renaissance anatomists' metaphorical understanding of the body as an underexplored territory with European explorers' and merchants' visions of the New World as an uninhabited wilderness ripe with natural resources to be harvested provides the foundation for this section. However, Sawday's story is one of exploration and exploitation. While the potential for exploitation and colonization always lurks at the boundaries of this metaphor—a fact I will acknowledge throughout this section— the focus of the metaphor in the way I am using it is not simply the discovery of the body, but also what remains hidden. As it evokes the intimate and yet detached relationship we

have with our bodies, this metaphor speaks to the disconnect between the scientific facts that describe how the body operates and how the body is experienced as lived.

The metaphor of the body as America resonates with the spirit of adventure and the captivating pull of the unknown. Under this metaphor, the body is a wilderness that defies all efforts to flatten its topography. Investigators play the role of cartographers, who seek geographical knowledge through the mediation of scientific instruments that survey, plot, and colonize the internal spaces of the body. Although great strides in anatomical knowledge have been made since this metaphor was first introduced in the seventeenth century, the nature of the body-subject still eludes precise measurement and defies simple reduction to a physiological mechanism. As a geographical metaphor, this idea of the body as America points to the large lacunae that exist between the subjective experience of the body and the objective measurement of its functions. As an alternative to the geographical and cartographical images that inform this metaphor, I will suggest that investigators engage their subjects along the lines of the pastoral image, which embraces the liminal spaces of the body.

From the Renaissance to the late nineteenth century, explorers, poets, and others have used different images to describe the wilderness of the American landscape. Throughout this section, I will argue that these same images inform the metaphor of the body as America. For body-subjects, the body is a newly discovered America in that its native inhabitants remain mysterious and savage, hidden beneath the skin. Its outlines and borders are amorphous and permeable. Indeed, twenty-first century American bodies are integrated seamlessly with various forms of technology. The mind expands into the surrounding environment and environment expands into the body. And yet, the territory of the body remains to be fully charted. The body continues to confound investigators and subjects just as the newly discovered landmass that would become America did the explorers of the sixteenth and seventeenth centuries.

As mentioned above, the metaphor of the body as America is constructed out of a wide range of images. At one end of the scale, seeing the body as America reveals the body as a wilderness that defies boundaries and is not encapsulated in any single description. The wilderness image describes the raw experience of the body as lived. At the other end of the scale, the body as America emerges as a charted territory on a map of the world that delimits, defines, and organizes knowledge. The cartographical image identifies the body as having a static landscape that can be traversed and mapped by those who are trained to recognize its unchanging landmarks. In the middle of these two extremes is the image of the body as a garden. The garden of the body presents an image of cultivated wilderness. This pastoral image places the cartographical model of the "American body" in conversation with the wilderness model. From within the pastoral image of the body, scientific and subjective schemas of the body exist in dynamic tension with one another. This tension is not resolved by the invocation of the pastoral, but merely identified by its discursive location as a midpoint between extremes at which the body appears as both sacred and profane and as subject and object simultaneously.

As in the previous section, my task in this section is to explore these metaphors as they arise within the American consciousness. They are already present from the beginning of the Republic and so are deeply engrained in the American psyche. In fact, they have been inherited from a European tradition that stretches back to Virgil. Drawing them out and showing how they provide an alternative metaphorical understanding of the body of the research subject is my task in this section. These metaphors are not buried somewhere within history, but are actively part of the American spirit of adventure.

To those familiar with narratives of illness, the myth of the journey is a commonly invoked concept used to help persons navigate their illnesses.[46] However, physicians and investigators have also found it useful. Surgeon and writer Richard Selzer

[46] See Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography* (West Lafayette, IN: Purdue University Press, 1999).

instructs his "young surgeon" to consider how, "in your littleness you descend for hours each day through a cleft in the body into a tiny space that is both your workshop and your temple … Every artery is a river to by forded or dammed, each organ a mountain to be skirted or moved."[47] To encounter the body of a patient or research subject is to embark on a journey of discovery. For some commentators, such as Paul Hodgkin, medicine is ideally a "collaborative exploration," an adventure in the sacred wilderness of the body where physicians' bodies are used to explore the bodies of their patients for the mutual goal of healing.[48] However, exploration of the human body for the purpose of medical research is a different kind of journey, one that is often not collaborative in nature. Indeed, the spirit of exploration as well as exploitation has driven the research enterprise since anatomists began dissecting bodies. Using the bodies of criminals and terminally ill patients or preying on poor and minority patients for access to their bodies is hardly a collaborative enterprise. Yet, the call to investigators to explore the body for research purposes did not begin solely with the intent to exploit. Instead, it had a quasi-religious mission—to tame the wilderness of the body and save the soul from destruction by the appetites of the flesh.

During the Renaissance, anatomists like Vesalius found themselves embarking on a religious quest to follow in the footsteps of the Divine Anatomist. As discussed above, this quest sought to discover the home of the soul within the flesh of the body. However, this quest was fraught with peril. For these men, the body as "'America' became synonymous with the triumph of the human imagination as it strove to unravel passages which seemed to become ever more tortuous, ever more complex."[49] This was a task that demanded not just reverence for the handiwork of the Divine Anatomist, but also the resolve to meticulously slice through the fabric of the body. Like the explorers of the

[47] Richard Selzer, *Letters to a Young Doctor* (New York, NY: Simon and Schuster, 1982), 49.
[48] Hodgkin, 1821.
[49] Sawday, 28.

New World, who encountered wild beasts, savage aboriginals, and a dense and forbidding land, Renaissance anatomists were often met with unruly and savage bodies that resisted their incursions.

Part of the resistance that the body seemed to display was a product of the perceived savagery of the human body as animal body. In the sixteenth century, Francis Bacon generated an image of the body as a complex of intersecting passageways, nooks, and crannies, whose multilayered structure was a consequence of its voracious appetite. Man was not simply a creature that thinks, but a creature whose passions and hungers formed his identity. As a savage instrument of its own passions, the "Baconian body bore in its design the signification of hitherto unknown space, concealing voracious and hence 'uncivilized' appetites."[50] These spaces needed to be civilized by the gaze of the anatomist. Exploration of the body offered the prospect of discovering and naming spaces that were predominantly uncharted and hid secret recesses where "the alien and savage 'other' could be located."[51] Rites and rituals of the flesh that the body hid tempted the anatomist as much as the physician. Discovery of these rites and rituals was akin to discovering the rain dance of the native American. Both bodies were seen as savage and in need of the civilizing gaze.

Anatomization was not confined to the body but became part of the zeitgeist of the Renaissance. Anatomists explored bodies as an expression of the introspective turn in literature and art. Sawday points to Sir John Davies's verse in *Nosce Teipsum* (1599) as illustrative of the broad impact of the wilderness metaphor:

> We that acquaint our selves with every Zoane
> And passe both Tropicks, and behold both Poles;
> When we come home, are to our selves unknowne,
> And unacquainted still with our owne Soules[52]

[50] Ibid., 95.
[51] Ibid.
[52] Ibid., 89.

Though this introspective turn was a collective project of thinkers like Montaigne and Davies, the body as America, like the recesses of one's own soul, resisted anatomization. The body's "expanses were so (microcosmically) vast, its recesses so hidden, that understanding followed only after the greatest exertion."[53] As mentioned above, Renaissance poets and anatomists were baffled by the mysteries of the innards of the body. They were forced to retreat to a skeptical view of both their bodies and souls for the "inwardly directed gaze traversed not simply regions of doubt, but transformed the body into the *locus* of all doubt. It was if the body had been rendered, in philosophical terms, alien territory."[54] It is intriguing to realize that part of what Sawday's history of anatomical research reveals is a sense of anatomists recognizing what occurs when the clinical gaze is reflected back upon themselves. In other words, a space has already been made within the tradition of medical research for investigators to practice self-reflection, especially as regards their own embodiment and their existence within the alien and savage land of the body.

In addition to the anatomical references mentioned above, images of America as a savage land also appear in the accounts of early European explorers and settlers. Of special interest here is the Puritans' sense that wilderness is unholy and needs not only to be settled, but also to be saved from the influence of the Devil.[55] While comparing modern investigators to Puritans might be unfair, the research imperative and the narrative of progress are both built on a rhetoric of productivity that sees the body as a wilderness that must be made useful. This rhetoric of productivity carries with it the presupposition that the body can be civilized and also purified through sacrifice on the altar of medical research. Nearly two centuries later, Andrew Jackson would call for the civilization of the wilderness as a matter of improving man's lot in life, thus calling into

[53] Ibid., 28.
[54] Ibid., 88.
[55] Roderick Nash, *Wilderness and the American Mind* (New Haven, CT: Yale University Press, 1967), 37.

question the intrinsic value of a life lived outside of civilization. In this rhetoric of "material progress, wilderness had meaning only as an obstacle."[56] Applied to the body, the mission this rhetoric persuades investigators to take up is clear. The wilderness must be swept away, charted, mapped, and controlled. If man is to save himself, he must first know himself, beginning with the wilderness of his own flesh.

Within the image of the body as a savage wilderness is an inherent impulse to conquer the exotic, the other, the savage body whose desires, emotions, moods, and needs seem to be beyond our control. In the act of investigating the savage body, some investigators have become savages. Others may fear this descent into barbarism and so adopt an attitude of detachment in order to help themselves deny the savagery of their own bodies as well as the savagery of the clinical gaze. These investigators turn to the rules and regulations of clinical research as arbiters of their own moral obligations to subjects' bodies as a way to avoid confronting the moral ambiguity of the face-to-face encounter. Yet, there are alternative readings of this image that value the body because of its savagery. These readings allow the investigator to adopt an aesthetic appreciation of the wilderness of their own bodies as well as the bodies of their subjects.

In the realm of everyday experience, the body-subject is the frontiersman who both sees his body as a wilderness and as a civilized space. In this sense, *civilized* is not taken to mean "colonized," but civilized in the sense that one has some control over his body, that he, in fact, lives through his body. The notion of *control* may be too strong a term to describe the entire realm of subjective experience, since there remain systems of the body over which one would not want to have control. Here one might think of the involuntary functions of the body: breathing, digestion, and heart rate, for example. Were intentional mental resources needed to monitor and execute these functions, the body might be seen as too civilized for its own good. Thus, we are left with a body that is only

[56] Ibid., 41.

partly consciously experienced. On this view, savagery is natural, and therefore, inherently valuable. It is contrasted with civilization in the sense that "civilization is pernicious also because it interposes a veil of artificiality between the individual and the natural objects of experience."[57] The experience of living on the frontier between pure savagery and civilization is an idea that is deeply rooted in nineteenth-century American life and so would have been part of the experience of late modern medical investigators.

Historian Frederick Jackson Turner in 1893 described the frontier as "the meeting point between savagery and civilization."[58] On Roderick Nash's view it is civilization that defines wilderness.[59] He notes that to the native peoples of America, nature was not wild and foreign, but home. The "'wild West' and the 'frontier' were products of the pioneer mind; so was the idea of wilderness."[60] If civilization is taken to mean an ordering force in the world, then the struggle to civilize the body is an ancient struggle. For example, the humoral theory of medicine was an attempt to place the inputs and excretions of the body within a system of thought that could be used to make predictions about how the body functioned under certain circumstances. Yet, along with these civilizing theories of medicine, bodies continued their resistance. Infectious diseases like the plague could not be explained satisfactorily with appeals to humoral medicine. Women's bodies were often poorly understood because they too failed to fit within systems of medical knowledge. The duality of the body as a space that is both civilized and savage lends itself to comparisons with the continent of America during the age of discovery, exploration, colonization, and expansion. Both harbor spaces that defy human control.

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[57] Henry Nash Smith, *Virgin Land: The American West as Symbol and Myth* (Cambridge, MA: Harvard University Press, 1950), 72.

[58] Ibid., 251.

[59] Nash, xi-xiii.

[60] Ibid., xiii.

Instead of rejecting the savagery of the American continent, and by proxy the body, Romantics in the late eighteenth and early nineteenth centuries introduced the notion of sublimity to describe the beauty of the uncultivated wilderness. Romantics favored the aesthetic appreciation of the chaos of the wilderness over the civilizing force of a pre-industrial European culture. Wilderness motifs in various works of literature "suggested the association of God and wild nature."[61] For example, in *Manfred: A Dramatic Poem* (1817), nineteenth-century English poet Lord Byron muses:

> There is pleasure in the pathless woods,
> There is a rapture on the lonely shore,
> There is society where none intrudes.[62]

For the Romantics, wilderness appealed to their delicate sensibilities and their highly attuned emotional intelligence. Wilderness evoked the passions of men who yearned for a deep connection to the spiritual and the emotional core of the natural world. This natural bastion of spiritual discovery was more primeval than even the body, which stood as the temple of the Holy Spirit.

Even American botanists, whose mission was to catalogue the natural history of the wilderness, felt free to stop to admire the "sublime enchanting scenes of primitive nature."[63] This kind of reverence for the wilderness is desirable because its presence tempers the scientific will to control. Like the anatomists before them, American naturalists allowed themselves to see the divinity in God's handiwork. In fact, the turn towards primitivism led to a belief that the purity of life in the wilderness could provide a new moral center for souls bred in civilization. Wild bodies were no longer seen as inherently evil but as evidence of divine revelation through nature.

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[61] Ibid., 46.

[62] Ibid., 50.

[63] Ibid., 54. Quoting William Bartram in *The Travels of William Bartram: Naturalist's Edition* (1775).

Transcendentalists like Henry David Thoreau saw even more clearly that spiritual truths about the world were hidden within the wilderness.[64] Like the natural world, the experience of the body as wilderness also has the power to enlighten. The unknown or poorly understood spaces of the body, like those of the wilderness, offer a chance to find "some grand, serene, immortal, infinitely encouraging, though invisible, companion, and [walk] with him."[65] Wilderness in this sense offers an opportunity to experience the Other, to see oneself as an enlightened creature that is both sacred and profane. Thoreau even embraced the wilderness and the "wildness … in our brain and bowels, the primitive vigor of Nature in us."[66] As the years passed, Thoreau would reign in some of his primitivism and adopt a more pastoral view of nature, placing himself among those sages who are able to draw on both the "wild and the refined."[67]

Contrasted with the agricultural metaphor, which presupposes that the body is a natural resource to be exploited, the pastoral metaphor in American and European thought applied to the body offers an alternative view of the body as a verdant, lush, and carefully maintained garden. Pastoral images in general appeal to a more innocent age. Placed within this context the body becomes a Garden of Eden prior to the Fall. Pastoral scenes are often bucolic representations of quiet pastures where shepherds tend their flocks. These scenes evoke the sacredness of the wilderness, revealing some hint of the divine plan in the construction of the body and in its perception. But the pastoral ideal differs significantly from the primitive ideal in that the former arises out of a tension between the natural and the artificial while the latter is simply a wish for a return to a primitive natural state. Defined by its opposites, industrialization, cosmopolitanism, and urbanization, pastoralism is a kind of escapism that when applied to the body speaks to the truth of how it is experienced, at least in health. To paraphrase Walt Whitman, the

[64] Ibid., 86.
[65] Ibid., 89.
[66] Ibid.
[67] Ibid., 92.

pastoral body is untamed and untranslatable into the language of medical science, for science is the tool of an ordered universe and the compulsion to name and thereby control the natural world.

Historian Leo Marx offers a rendition of a notebook entry made by Nathaniel Hawthorne as an illustration of the pastoral image in literature. According to Marx's retelling, Hawthorne is deep in reverie in the woods near Sleepy Hollow, New York, when he is disturbed by the sound of a locomotive that "brings the noisy world into the midst of our slumbrous peace."[68] Hawthorne's story evokes the interruption of the lived experience of the body and the intrusion into the quiet spaces of the body by the instruments of science, industry, and quantification. Into the reverie marches the "fragmented, industrial style of life that allegedly follows from the premises of the empirical philosophy."[69] From the synthetic moment where the natural world and Hawthorne's quiet reflectiveness coalesced into a harmony, the dissonance of industry burst onto the scene to draw him back into a life he had tried to ignore. The harmonious relationship between man and nature is channeled through the body as it is lived in the everyday experience of the world. Pastoralism is "located in a middle ground somewhere 'between,' yet in a transcendent relation to, the opposing forces of civilization and nature."[70] In this sense, the pastoral body is a site for the civilizing and colonizing forces of scientific inquiry as well as a site for self-discovery through exploration of the experience of embodiment. It is precisely this liminal space that clinical investigators should inhabit, along with research subjects.

Part of the pastoral metaphor is the cultivation of the senses, the aesthetic approach to life that sees beauty in the smallest aspects of nature. Travelers to the New World during the seventeenth and eighteenth centuries brought back tales of beautiful

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[68] Leo Marx, *The Machine in the Garden: Technology and the Pastoral Ideal in America* (New York, NY: Oxford University Press, 1964), 13.

[69] Ibid., 18.

[70] Ibid., 23.

sensory delights that broadened the imaginations of their compatriots. Though the mythical utopian lands of Arcadia and Atlantis had been part of the European folklore for generations, the New World offered the hope that these pleasures could be realized. As a part of the wilderness metaphor, pastoral imagery draws attention to the body as an organ of sensation. Living through the body means enjoying the pleasures that embodiment offers. Life lived as a garden of sensory delights is sweet indeed.

The agrarianism of Thomas Jefferson adds another layer to the pastoral metaphor in that he valorizes the American labor forces and consequently the bodies of American workers, for the "rural virtue" that working in the fields affords them.[71] He "rejects productivity and, for that matter, material living standards, as tests of a good society."[72] Likewise, the pastoral body is not beholden to the discourse of productivity, but enlarges the discourse of being. Instead of the industrial body as *homo oeconomicus*, the pastoral body represents *homo poetica*, or for Jefferson, *homo faber*. The Jeffersonian man is self-made, shaping his environment and making meaning out of his existence without succumbing to the caprice of external social facts. For Jefferson, industrialization lurks like a disease—a "canker which soon eats to the heart" of the body politic.[73] The metaphorical representations of pastoralism highlight the often jarring juxtaposition of the symbolic representations of industrialization against a bucolic mixture of wilderness and cultivation.

[71] Marx, 144.
[72] Marx, 127.
[73] Marx, 125. Quoting Thomas Jefferson, *Notes on Virginia*.

Figure 5: George Innes, *The Lackawanna Valley*, c. 1856. Oil on Canvas. **Courtesy National Gallery of Art, Washington.** Reproduced from: http://www.nga.gov/fcgi-bin/tinfo_f?object=30776.

Visual images such as George Innes's *The Lackawanna* Valley represent themes of the pastoral in ways that capture the spirit of this metaphor as it applies to bodies (Fig. 5). Interpreting Innes's work requires the viewer to take in the detail of the piece, describe and analyze its composition, and interpret its meaning while responding to its affective and aesthetic effects. A brief description of the work might begin by noting how the eye of the viewer moves from the tall tree in the left foreground down to the figure reclining below it. The eye then moves along the fence line where it is met by a shape that seems out of place in the bucolic midground. Tracing the locomotive and its smoke trails back to the center of the piece, the eye is drawn to the shapes of buildings and what appears to be a gigantic roundhouse in the middle of the painting. As the eye recedes to the background it is met with the shapes of rolling hills and verdant pastures once again.

In following the composition and organization of Innes's work here, it is clear that there is a tension between the symbols of industry, the trains in the fore, mid, and background, and the natural landscape of the surrounding forest and hills. The train in the foreground slices through the belt of trees in the midground, seeming to burst in on the quiet tranquility of the figure in the foreground's reverie. Yet, when one looks closer, the shapes of stumps of fallen trees indicate that someone has already been hard at work clearing away the land and placing fences on it to demarcate his property from his neighbor's. Civilization has already intervened here, the spaces for reverie are limited to the shade of the tall tree in the foreground and the tree line in the middle and background. How does the organization of this painting work symbolically, especially with regards to how the figure might view himself and how the viewer is meant to feel about this scene? A primitivist might decry the violation of the natural landscape and see the reclining figure as a fellow lover of nature who is distraught at the invading forces of industrialization. On the other hand, the industrialist who commissioned the work would likely see the fallen trees, the gigantic roundhouse, and the fleet of locomotives as a sign of progress.[74] The hideous wilderness has at last been tamed and man is in control once again. Clearly there is some sympathy for this view in the images, as the town below is likely dependent on the railway, which seems to be transporting coal from a nearby mine. It too has been industrialized.

Innes's work has symbolic value for the pastoral image of the body. The railway cars that cut through the wilderness of the forest symbolize the progress narrative that drives medical research. For investigators the railroad stands as a symbol of the medicalization and industrialization of the body. Just as railroads drove economic progress in the nineteenth century, so medical experimentation stands as the engine that

[74] See the National Gallery's description of Innes's work. Available from http://www.nga.gov/fcgi-bin/tinfo_f?object=30776. John Jay Phelps was the founder of the Delaware, Lackawanna and Western Railroad and commissioned the work by Inness.

shifts the balance of the pastoral body to the industrialized machine body. Industrialization is both a fragmenting and a unifying force. Of course, to the research subject the body is both civilized and wild. For most, it is a wilderness that should be protected from invaders. The frontiers of the interior of the body as American wilderness maintain the integrity of the body-subject by offering access only to invited guests. Within the wild spaces of the body dwells the mystery of life. This mystery is deeper and more profound than can be explained through science or explored through medicine. Maintaining the purity and the mystery of these spaces is as challenging as resisting the force of the mighty locomotive. Yet, there are voices from within the pastoral tradition that are able to speak to these challenges and in so doing illuminate the mysteries of the body as it is tied to the American soil.

As the physical frontiers of the West disappeared in the nineteenth century, poets turned to the frontiers of the body in an attempt to show how these bodily spaces were the next frontiers. Though they too had been explored, human bodies still mirrored the vastness and sacredness of their geophysical counterparts. As Innes's image shows, the victory of civilization over wilderness threatened to constrain and denigrate the sublimity of the natural world. After the Civil War, which pitted bodies grown from a common American soil against one another, poets like Walt Whitman sought to rejuvenate themselves and the image of the American body by uniting the two in verse. Nash refers to Whitman as a "precursor of the American celebration of savagery."[75] It is in this celebratory mood that he sings his songs of the American body.

Whitman's affection for America is drawn from his love of the native soil that nurtured the growth of his imagination and his body. Whitman in "Song of Myself" uses the idea of his body as an America to celebrate himself and rejoice in the joy of living. His molecular genealogy is homegrown and expressed thusly:

[75] Nash, 151.

> My tongue, every atom of my blood, form'd from this soil, this air,
> Born here of parents born here from parents the same, and their parents the same,[76]

The tongue he uses to sing the praises of his native land is carved from the same American air that fills his lungs. His body would not sing these praises were it not so formed. His life as a body-subject would be incomplete without its ties to the land.

As has been mentioned above, comparisons between natural landscapes and the organization of the body are not uncommon among poets. They emanate from a primeval understanding of the body as a natural, but not biological, object. Whitman's verse captures the pride that he has in the "Americanness" of his body. For him the land and his body are indistinguishable. They are made from the same material. He writes in "Song of Myself":

> My ties and ballasts leave me, my elbows rest in sea-gaps,
> I skirt sierras, my palms cover continents,
> I am afoot with my vision.[77]

Here Whitman explores the image of himself gliding over the American continent. Through this image he frees himself from the bonds of social life and expands his sense of self across the land. His moral and aesthetic vision stretches from the Atlantic to the Pacific. His only limitations are his senses. His body as America unites land masses across the sea. He is a living bridge between the nineteenth-century Romantics and the industrialization of the twentieth century.

Whitman also saw that the America he loved could be anthropomorphized into the human form that he celebrated with his verse. Though states and territories had partitioned and divided the land along political boundaries, Whitman saw the potential for unity. In "Our Old Feuillage," he describes America as a vast democratic body, where

[76] Whitman, "Song of Myself," 22.
[77] Ibid., 49.

regions are united by both geography and a common love of country. Describing the diversity and beauty of the Great Lakes region, he remarks, "Always these compact lands tied at the hips with the belt stringing the huge oval lakes."[78] In fact, the entire poem is an extended ode to the beauty of the American wilderness as well as the beauty of its people:

> Singing the song of These, my ever-united lands,--my body
> no more inevitably united, part to part, and made out of a
> thousand diverse contributions one identity, any more than
> my lands are inevitably united and made ONE IDENTITY [79]

His anatomization of America is an anatomy of sublimity and a deliberation upon the parts that construct the whole of the American body he loves. In his analysis of the inner spaces of the American landscape he not only tolerates but celebrates the ambiguity of the American body and identity.

In "Song of Myself," Whitman paints the portrait of Americans at work and at play. To complete the portrait, he places himself in each of these roles. His America is a dichotomous network of free men and slaves, activity and relaxation, sacredness and profanity. His body is composed of Yankees and Southerners, old men's bones and young men's muscles. By combining aspects of American life and characteristics of its citizens that seem to be mutually exclusive, Whitman draws attention to the liminal spaces that inhabit the image of America. Though some have described it metaphorically as a melting pot, America is a land of contradictions. Likewise, the body as America is also a land of contradictions. Whitman's verse does not seek to explain these contradictions, but revels in them, celebrates them as counterpoints within the melody of his song. The contradictions of pastoralism in general are made clear in sections of Whitman's *Song* that alternate between rejection and approval of the work of medical and physical science. As a naturalist surveying the land and as an anatomist dissecting his

[78] Walt Whitman, "Our Old Feuillage", in *Leaves of Grass (1892)* (New York, NY: Bantam Books, 1983), 138.

[79] Ibid., 141.

own body, Whitman declares, "Having pried through the strata, analyzed to a hair, counsel'd with doctors and calculated close / I find no sweeter fat than sticks to my own bones."[80] Here Whitman has analyzed himself, compared his notes with the medical staff, and found himself unwilling to judge the foibles, appetites, and follies of other men. He is proud of his own appetites and does not pass judgment on those who live off of the fat of the land for he too delights in earthly pleasures. His attitude here is reminiscent of the speaker's conclusions in "When I Heard the Learn'd Astronomer." The stories told by doctors and astronomers are interesting, but they leave out the most choice cuts and delicious features of life in their attempt to know and control the world. He expands on this notion in another passage from *Song of Myself*. After extolling the virtues of mathematicians, geologists and physicians, Whitman confesses that they merely point to truths about the world, but do not inhabit it. He declares,

> Gentlemen, to you the first honors always!
> Your facts are useful, and yet they are not my dwelling
> I but enter by them to an area of my dwelling.[81]

In this passage, Whitman outlines the fundamental world view of Romantic pastoralism. Pastoralists are conversant in both facts and values. They inhabit the liminal space between these two ways of knowing the world. The pastoral body also inhabits the space between the body-object and the body-subject. The pastoral body as lived experience is lived between the civilizing force of human endeavor and the wilderness of our savage animality that permeates each human being.

Throughout this chapter, I have noted the tension within the metaphor of the body as America between forces that wish to colonize the body and those that find purity and joy in the mysteries of the flesh. As part of the spectrum of images that compose the metaphor of the body as America, the cartographical image highlights this tension the

[80] Whitman, "Song of Myself," 38.
[81] Ibid., 41.

most clearly. To speak of the body as an America is inevitably to invoke the image of the body as a territory that has been discovered, explored, and mapped. Conversely, the idea of the body as a sacred wilderness presupposes "a 'not cartography' land where lurk[s] an army of inaccurate, heretical, subjective, valuative, and ideologically distorted images."[82] When the body speaks, it often blasphemes scientific images of the body. It is a heretic, a treacherous range of mountains and caverns that turns back the intrepid explorer and defies cartographers. While subjects' bodies appear to investigators as well-charted lands, the body as lived has its own topographies, indices, legends, and latitudes and longitudes. To encounter the research subject's body from the outside is to see the land as ripe for colonization, while to experience it from the inside is to see it as homelike, but also uncanny, hidden. It is a land that is already inhabited, that has its own customs, rituals, and traditions. Bodies are Americas that are marked by their experiences of the world, that already have their own landmarks, but also their mysteries, their forbidden forests, and their own dark continents.

According to the history of the body left by the Renaissance anatomists, there no longer are any dark continents. Their descendants have refined techniques for peering into the spaces of the body without cutting them open. Functional MRIs claim to determine states of mind from the observation of oxygen levels in the brain. The maps of the body are being rewritten with the aim of producing "a 'correct' relational model of the terrain. Its assumptions are that the objects in the world to be mapped are real and objective, and that they enjoy an existence independent of the cartographer; that their reality can be expressed in mathematical terms; that systematic observation and measurement offer the only route to cartographic truth; and that this truth can be independently verified."[83] Indeed, the explorers of old "[left] their mark on the body in

[82] Mary Rosner and T.R. Johnson, "Telling Stories: Metaphors of the Human Genome Project," 10, no.4 *Hypatia* (Fall 1995): 116.

[83] J. B. Harley, "Deconstructing the Map" *Cartographica* 26, no. 2 (Summer 1989): 4.

the form of features that were mapped and named and inhabitants who were encountered and observed."[84] Physicians, pathologists, and anatomists explored parts of the body and claimed them for their own. As Sawday notes, Eustachius claimed parts of the ear, Fallopio claimed the tubes that now bear his name, and Langerhans established his namesake islands in the pancreas.[85] In fact, the body is dotted with names of explorers who have staked their claim to the various organs, tissues and spaces within the body.[86] In this sense, the body has already been quite literally claimed for science.

The cartographical image for the Renaissance anatomists operated under the assumption that "once uncovered, the body-landscape could be harnessed to the service of its owner."[87] One of the more generous readings of this claim implies that the anatomist/physician/cartographer thought that his act of naming would not change the landscape. Instead of trying to own the landscape and harness it solely for his own use, he would then return it to its rightful owner and proceed to share his map with the natives. Under this interpretation, what was called for was not a new regime of power legitimized by the maintenance of a particular form of knowledge production but permission to enter and map a space so that the natives could find their way around. While this is still a paternalistic project, it does not have the colonial undertones of the reading of this project given above. In this sense, maps of the body were needed to change the vision of the body-subject from a reader of "semi-mythical traveler's tales" to tales told by science and oracular empiricism.[88] Unfortunately, the mapping strategy used then, and still used today, is the mechanical metaphor. This metaphor as mapping strategy for charting the spaces of the body is a relic of the anatomical and physiological discoveries of Vesalius and Harvey.

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[84] Sawday, 25.
[85] Ibid., 23.
[86] Ibid.
[87] Ibid., 25.
[88] Sawday, 26.

Anatomists after William Harvey were forced to account for his mechanical/hydraulic explanation of the circulation of the blood. This mixture of materialist and vitalist models of the body emerged as a mapping strategy when the geographical metaphor that preceded it illuminated a landscape that was too remote, too complex, and too daunting. Like a bulldozer plowing through the forest, reductive materialism flattened the topography. It sought to erase the wilderness and replace it with a well-marked path through the great cities of the body. This mapping strategy is an integral part of the rhetoric of reductionism.

As Rosner and Johnson argue in their study of the rhetoric of the Human Genome Project, "maps continue to be both ideological and rhetorical."[89] Those who control the mapping strategies determine which metaphorical understandings of the body will be permitted and which will be omitted. Indeed, the entire process of cartography is an exercise in reduction and oversimplification. Investigators as cartographers of the body determine what is relevant and discard the rest. They follow the rhetoric of reductionism in the visual maps of the body that they construct. Illustrations used in medical journals are kinds of maps of the body. They rely on captions to explain the action and chart the territory. Furthermore, cartography is a kind of inscription. Visual images used as maps are inherently reductive and seek to standardize objects according to a lexicography conceptualized by the cartographers. A map is not a landscape.

After the West was settled in the late nineteenth century, the wilderness regained its pastoral ideal as an asylum from the pressure and stress of civilization. Nash argues that this shift in moral vision regarding the wilderness ushered in a new tolerance for wilderness as spaces that had "existence rights totally independent of their use for people."[90] In this same vein, the body as wilderness or as savage land may be entitled to the same level of respect and reverence for wilderness shown by the establishment of the

[89] Rosner and Johnson, 116.
[90] Nash, xiv.

system of American national parks and wildlife refuges. Investigators should show reverence for the "wilderness" of the body as a "sanctuary in which … [one] can find respite from the pressures of civilization."[91] Nash's etymology of the term *wilderness* points to an idea of a space that is uncontrolled, unruly, and willful.[92] Indeed, the body is often imagined as a space that has its own will, which operates against the self and places itself in opposition to the subjectivity of the self. As this chapter has shown, to speak of the body as an American wilderness is to invite ambiguity. From the perspective of the explorer, wilderness is a frightful and evil place that must be colonized and controlled. From the perspective of the inhabitants of the wilderness, it is place where one need not fear being lost.

Although the metaphor of the body as America is a tempting alternative to the agricultural metaphor, if not the other two discussed above, the complexity of the images that inform it may make it too unwieldy to capture the essential features of the body-subject. However, its function as a foil to metaphors of the body that render it "in terms analogous to the land of the nineteenth century--that is, as an exploitable natural resource whose contents are of more interest than is the integrity of the whole" is helpful for broadening the notion of respect for persons currently active in the bioethics literature.[93] Nonetheless, the metaphor of the body as music may be able to speak to some of the more pressing moral problems associated with the rhetoric of reductionism in a language more familiar to investigators. It is in the spirit of seeking common ground on which to build a more capacious sense of respect for persons that I now turn to consider the body as music as a third alternative to the mechanical, industrial, and agricultural metaphors.

[91] Ibid., 4.
[92] Ibid., 1.
[93] Campbell, "Religion and the Body in Medical Research," 279.

Chapter 4: Listening for the Song of the Other

The metaphor of the body as music allows for symbolic representations of the body-object and the body-subject to coexist within a uniform discourse of embodiment. Normatively speaking, the metaphor of the musical body supports the development of an ethos grounded in recognition, reciprocity, and respect. This normative foundation is rooted in the experience of embodiment as the source for the investigator-subject relationship. Using Emmanuel Levinas's theory of the face-to-face encounter to flesh out the normative implications of this metaphor, I argue that the imperative to respect persons is enlarged through a view of research ethics as improvisational. I begin this chapter by discussing the idea of the Other as the source for the investigator's fundamental moral obligations. These obligations are revealed in the face-to-face encounter, a topic I discuss in greater detail at the end of the chapter. Levinas's ethics of the face reveals a way to recognize the essence of the Other that precedes language. It is in this prelinguistic awareness of one another as fellow body-subjects that caring for the Other develops. In these moments of awareness, the idea that we all share bodies that may be listened to, seen, felt, and interpreted by one another becomes reified in our speech and our gestures. Body-subjects need to learn to recognize one another in order to initiate dialogical relationships. Investigators must learn to recognize that their obligations to the personhood of the subject precede their epistemic obligations to scientific knowledge. Only by recognizing the face of the Other as symbolic of those obligations can investigators hope to ground their exploration of the body in an ethic that genuinely respects persons. The nature of this encounter with the body of the Other is the subject of

the second section of this chapter. In the description of this encounter we find the intertwining of the metaphorical representation of the body as music and the ethical obligations that flow from encountering the body of the Other as such. In order to aid the investigator in recognizing these obligations, I will need to develop a phenomenology of the encounter with the face. This necessarily involves a description of how the senses attune themselves to the body of the Other. Seeking out the body of the Other is a matter of aligning the senses of hearing, sight, and touch to the essence of the face as it presents itself. Listening for and answering the call of the Other is a task that requires investigators to improvise their relationships with subjects so as to extend them deeper and more broadly than the regulations and rules governing human subjects require. The call of the Other is the call to moral responsibility via "the face [that] summons me to my obligations and judges me."[1] During the course of the trial, investigators and subjects will encounter circumstances that will compel them to move beyond the consent document but still maintain the harmonious and collaborative relationship upon which ethical science is built. This ethical give and take resembles jazz improvisation in the demands that it makes of each "player." In order to begin this process of improvising, the body of the Other must first be recognized.

WHO IS THE OTHER?

Throughout this dissertation, I have spoken of the Other as a kind of ethical construct around which one's moral obligations are to be deciphered and expressed. To be clear, Emmanuel Levinas and Jean-Paul Sartre have significantly different interpretations of the Other. However, both Sartre and Levinas use the term to indicate

[1] Levinas, 215.

the other person as well as an Otherness that is absolutely Other. In most cases, I use the term to describe research subjects as seen from investigators' eyes, though the subtext of radical alterity remains intact as an assumption that compels body-subjects to seek the Other. The Other is the research subject standing before the investigator in the clinic and the hospital. Of course, this construct necessarily abstracts from the actual experience of meeting another person in the research context. Nonetheless, with this caveat in mind, investigators' ethical responsiveness to any research subject emanates from the same source. For Levinas, this Otherness may be interpreted as the Absolute Thou from which our moral obligations flow. The other person is an instantiation of the Other, which is to say that through our experience of the other person we approach absolute alterity.

Although both Sartre and Levinas define the Other by its radical alterity, the consequences for research ethics of this alterity are quite different. For Sartre the Other is a threatening presence, a radical negation of the self that limits the possibilities of the subject. The Other in this case stands outside of one's moral universe. One cannot generate intersubjectivity with the Sartrean Other because there is no means for reciprocal recognition through the acknowledgment of similarities. Sartre is also uncomfortable with making the Other constitutive of the world of the subject. In Sartre's view, the Other "is presented in a certain sense as the radical negation of my experience, since he is the one for whom I am not subject but object."[2] For Sartre, the Other is the "not me." To the Other, the subject is simply another object in his world. Sartre seems to suggest that the very alterity of the Other precludes the possibility of intersubjectivity as a space for moral reciprocity.

[2] Sartre, 228.

Conversely, the radical alterity of the Other in a Levinasian sense is the very foundation for intersubjective relationships. Within the research enterprise, the relationship of intersubjectivity is established by an invitation to intercorporeality. In this context, *intercorporeality* is taken to mean the ritual tactile interaction of the research subject and the investigator either through personal contact or as mediated by scientific instruments. All too often, it is assumed that this relationship is covered by the consent form. However, the relationship of touch whereby the investigator is granted access to the intimate spaces of the subject's body is a matter of traversing a great moral divide. It is not a responsibility that can be encapsulated by a mere document but must be rooted in a relationship between persons that is built on respect for the Other. Since humans are embodied, it is possible to traverse the gap between persons by tracing out their relationships along the lines of intercorporeality. As with other human relationships, the investigator and subject are joined through bodily empathy with the body of the Other. For that reason, moral obligations begin with the bodily recognition of the Other as both same and Other. However, neither Sartre nor Levinas are able to extend moral reciprocity along the lines of embodiment. Instead, there is an implied ethics of responsibility that begins with the face of the Other and, for Levinas, is expressed through language. Though Levinas's ethics begin with encountering the face of the Other, the relationship is always asymptotic. The very alterity that summons the self to the Other and provides the impetus for moral obligations to the Other seems in Levinas and Sartre to generate an unbridgeable divide between the self and Other.

Although investigators and research subjects have different reasons for entering into the clinical space, their relationship is intentional, not accidental. They have not been

brought together by chance or because of some injury or illness that has disrupted the lifeworld of one of them. On the surface, at least, it would appear that they have chosen to meet in the clinical space. However, for Levinas the ethical encounter with the Other arises from an innate "metaphysical desire" for the absolutely other that only grows with each encounter.[3] This is a hunger that cannot be satisfied, a yearning that does not bring intimacy, but only distance. This relationship can only be with another who is also a subject, who is also an "I" in Levinas's nomenclature.[4] The Other is not simply the negation of the self, since that entity would still be constituted by the "I." The Other is the stranger who "escapes my grasp by an essential dimension, even if I have him at my disposal."[5] To make the Other part of my world would be to violate his freedom. For Levinas, to do so would be an injustice. Put another way, the Other overflows my idea of him.[6] And yet, this overflowing does not preclude the possibility of a moral relationship with the Other. In fact, this overflowing of thought and the alterity leads to "'resistance' of the other [that] does not do violence to me, does not act negatively; it has a positive structure: ethical."[7] This resistance is not only an acknowledgment of our essential difference but also the boundaries of our moral obligations to one another. This means that for Levinas an encounter with the Other must lead to the recognition of mutual moral obligations to refrain from harming one another.

For Levinas, radical alterity is meant to ward off any attempts to subject the Other to a system of totalizing thought within which I can limit his freedom. However, while it seems that the Other may be outside my experience, he does structure my experience in

[3] Levinas, 33.
[4] Ibid., 36.
[5] Ibid., 39.
[6] Ibid., 87.
[7] Ibid., 197.

that he represents the limits of my experience to me. In fact, Levinas argues that through language (either bodily or verbally conveyed) he draws me in to his alterity, whether he wants to or not. Even if his gestures are standoffish, indifferent, or blatantly hostile, they are identifiable because of their relationship to my world, the background of his world. This sense of representing through his mere existence the limit of my world expresses the fundamental moral and existential tension that arises when considering how subjects view other subjects as objects. Knowing the Other as merely an object would seem to undermine the very moral foundation Levinas wishes to establish, since objects do not limit but merely exist within one's own world. Only subjects can limit other subjects. Furthermore, both Sartre and Levinas argue against the idea that knowing should be the measure of being, as it is for Husserl. On their view, attempts to know the Other diminish his freedom. Instead, the subject's relationship with the Other should be ethical and existential, not merely epistemological. The metaphor of the body as music encapsulates all three of these elements.

LIVING THROUGH THE MUSICAL BODY

Music is ever present in our modern world. Whether it is the sound of garbage trucks loading refuse into their compartments or the sound of Jamaican ska playing on the radio, aside from those who have suffered severe hearing loss, we all experience sound as part of our lived experience. Even public spaces are filled with music. Dining in nearly any restaurant in America is normally an experience set to music. Motivated by the effect that music has on consumption patterns, retailers have deemed public spaces as performance spaces. Yet, curiously hospitals and clinics are normally devoid of music. While one's ears may be assailed by the strains of Muzak versions of classic songs from

the 1980s in the elevators of any modern clinic, the only music one is likely to hear once he enters the wards is the sound of equipment used to monitor vital signs. Moreover, these machines simply reproduce the music of the body, giving expression to the metaphor I will explore in the following pages.

Simply put, the metaphor of the body as music compares the experience of hearing, playing, and reading music to the experience of embodiment. Uncovering the layers of this metaphor reveals an array of normative and epistemic content. Epistemically, this metaphor taps into some overlapping ideas about how to study the lived body as well as the body as scientific object. More specifically, it addresses some aspects of the lived experience of embodiment that are not adequately captured in other metaphors. For example, to say that the body is a text is to illuminate many features of the body as an object to be read and inscribed. Also, seeing the body as text does capture some elements of the lived experience of embodiment. Some individuals would be comfortable describing their bodies as instruments of inscription that write the story of their lives. However, this notion of the instrumentality of the body as a tool of inscription abstracts the lived experience from living itself. It places the body as an object within a realm of a purely cognitive analysis of embodiment. To see one's life as a text is to erase from the lived experience that which eludes expression as a text. It places the experience of embodiment apart from the experience of living through the body. It cannot account for that which is visceral about life. There is a permanence to the notion of the body as a text or as an instrument of inscription that abstracts from the impermanence, fluidity, and uncertainty of life as it is lived. Within the metaphorical space of the body as music these elements of inscription are only part of the experience of life as it is lived through the

body. There are several core features of this musical metaphor that capture the essence of the lived body with more elegance than the textual metaphor. Notions of harmony, discord, volume, tempo, rhythm, and style are essential to an understanding and appreciation of music. Though one could speak of the rhythm and tempo of a text, these terms are more expressive when they are used to describe one's observations about the body. While this metaphor of the body as a text is on the whole inadequate, there are aspects of the musical metaphor that resemble texts in that they originate with speech and verbal expression.

The metaphor of the body as music is not limited to sounds made by musical instruments alone. This metaphor also captures verbal expression before it becomes inscribed. Tonal or lyrical vocalizations like singing, rapping, and scatting announce themselves prior to inscription, where words emerge as interrogative, subjunctive, imperative, and evocative. Furthermore, recorded vocal music is free of the kind of violence of other forms of inscription as it authentically captures some of the visceral elements of musical expression that are untranslatable into text. For example, simply reading aloud Abel Meeropol's lyrics to Billie Holliday's version of "Strange Fruit" is necessary for understanding the theme of the song but is hardly sufficient for capturing its essence and its meaning. In order to understand the brutality of the images Holliday's rendition evokes, one must listen to her voice as she sings "Scent of magnolia sweet and fresh / Then the sudden smell of burning flesh."[8] Her diction as she begins the second line explores the irony of the contrasting smells and creates a vivid emotional response to the tragedy of Southern racism not fully present in the text itself. Holliday's melancholic vocals rise and fall with her description of the "gallant South" and the fruit of Southern

[8] Lewis Allan, "Strange Fruit," (1940). http://www.pbs.org/independentlens/strangefruit/film.html

bigotry and violence. Despite the clear value of hearing music as opposed to simply reading a transcription of the notes, composition, and lyrics, there is also extraordinary epistemic value in learning to read the text of the musical body.

The metaphor of the musical body also supports scientific investigation. There are similarities between the methodology of medical research and the methodical study of music appreciation and musical composition. Just as musicians compose, analyze, and read sheet music in order to discover the basic structure of a musical piece, investigators must be able to decode the music of the body in order to pursue their research. Investigators are adept at discovering patterns and rules that support the nomothetic ordering of biological life. Songwriters also adhere to a set of general patterns, scales, modes, etc., in order to produce harmonies and melodies. For example, "music making as a temporal art is a nonlinear (although sequential) pattern of audible diversity that transforms seeming fragmentation and chaos into a discernible pattern or configuration."[9] Through the careful consideration of potential variables and the placement of strict controls on these variables, investigators also attempt to bring order to chaos. Furthermore, there is an observational and empirical component to the study of music and the study of the body as a scientific object. Studying the physics of music necessarily requires an appreciation for the physiology of the body. In addition, creativity in music making and medical research also share other epistemic features. Each starts with a hypothesis about the significance of a particular pattern. Musicians test this hypothesis by constructing

[9] Phyllis A. Updike, "Aesthetic, Spiritual, Healing Dimensions in Music," *Art and Aesthetics in Nursing* 14, no. 2611 (June 1994): 294.

To play or listen to music is to inhabit a dynamic world whose "structure permits the individual maximum engagement: projection of his or her own unique experience free of external artistic definition of that subjective experience."[10] The search for meaning in musical performances is an exercise in exploring ambiguity. Revelations about the notational and mathematical structures that underlie musical compositions hold the promise of unlocking the mystery of music. Appreciation of the intricacies of a fugue, for example, reveal a mathematical sophistication that is as aesthetically pleasing as hearing Bach without understanding how the piece was constructed. Furthermore, there is no one way to interpret a musical piece. For example, a song by British pop/reggae band The Police called "Every Breath You Take" is often played at weddings or on other occasions where a romantic mood is intended. The speaker of the line "every breath you take, every move you make, I'll be watching you" is often interpreted as a loving presence that seeks to protect and nourish his lover. However, in an interview with Sting, the lyricist, lead singer, and bass player, he admitted that, "On a first hearing it could just be a pretty love song, however on repeated listens the mood becomes more sinister as you realise that this love is of an obsessive nature."[11] He goes on to say, "I think the song is very, very sinister. It's jealousy and surveillance and *1984*."[12] The multiplicity of possible interpretations of any particular musical composition lends credence to the idea that the body as music may also be interpreted in a variety of ways. This metaphor provides an ideal context within which scientific, mathematical, and quantitative analyses may

[10] Ibid., 292.

[11] Sting, Interview with Annie Nightingale, *Sold on Song* BBC Radio 2, accessed November 26, 2012, http://www.bbc.co.uk/radio2/soldonsong/songlibrary/indepth/everybreathyoutake.shtml.

[12] Ibid.

capture salient features of the lived experience of embodiment while maintaining the value of the lived experience itself.

In order for the metaphor of the musical body to be able to integrate objective and subjective understandings of the body, the lived experience of the body must be shown to be translatable into metaphorical terms. Like most art forms, the shape of music "may be compared to the shape or contour of a life—the rhythm, pulse, peaks, and troughs that characterize any consciously lived human life."[13] Music has many of the core features of embodiment. Stripped down to its essence, it reveals itself as movement in time and space. From the beginning of a song to its conclusion, there is progression across some previously demarcated dimension of time, which is marked according to how the space is to be filled. The lived experience of everyday projects in the world is measured by these same dimensions, among others. Integral to an appreciation of time and space within the lived experience of the body is the notion of rhythm.

Life has a particular rhythm to it, expressed through bodily intentionality in the world. This rhythm tends to be covered over in everyday experience, yet illness, injury, and any other occasion which may cause one's consciousness to break with its absorption in the tasks of the world will ultimately reveal its meaning structure. One of the more clear examples of how the rhythms of life are made manifest is sleep disruption due to travel across time zones. While the difference of an hour or so may not matter to most people, significant changes in the way that time is observed in different geographical locations normally has a disruptive effect on the human body. Bodies perceive changes in time according to the pattern of the rotation of the earth. The circadian rhythm is a biological adaptation to the rotation of the earth via a synchronization of the metabolic,

[13] Updike, 292.

hormonal, cardiovascular, and central nervous systems to a twenty-four-hour cycle of wakefulness and sleep. It stands as a prime example of how the body has its own rhythms. In order for one to feel in tune with his environment, he must try to manage his life so that it approximates this cycle. Too much or too little sleep often has a negative effect on one's ability to function. In Mircea Eliade's elegant phrase, "the cosmic rhythms manifest order, harmony, permanence, fecundity."[14] Though Eliade is speaking here about seasonal changes, which affect bodily rhythms on a much longer timescale, the same sentiment holds true for daily rhythms.

Another more intimate and oft-noticed set of rhythms is the pulse and respiratory rate. Like rhythms in music, the pulse is measured in beats per minute. In fact, there are few rhythms that are more important for sustaining life than the heartbeat. The pulse has a long history in medicine of being an indicator of disease and health, while outside of medicine the term is often invoked rhetorically when referring to an integral element of any enterprise. For example, in the business world to have one's finger on the pulse of the market is to have profound insight into the current state of the economic situation. Respiration is also measured in breaths per minute. These values are not normally noticed during the lived experience of health. However, there are instances where these values become quite important, as when exercising or monitoring one's health or the health of others. Furthermore, the music of the body as indicated by the pulse and the breath structures some of the literary arts. Ralph Waldo Emerson noted that in poetry, "Metre begins with pulse beat, and the length of lines in songs and poems is determined by the

[14] Eliade, 117.

inhalation and exhalation of the lungs."[15] Harmony of thought and breath is necessary for artistic expression as well as human health.

Dynamics in music also have analogues in the experience of embodiment. Hushed, whispering violin tones such as those that begin the second movement of Ludwig von Beethoven's Symphony No.7 in A Major Op. 92 draw the listener in to the melancholic world that the composer has created. On a laptop computer with lousy speakers, one has to strain to hear the melody as it rises from a few violins playing in perfect harmony. Soon the woodwinds join in on the theme, which disappears after a few bars into a rising and falling tide of pastoral images. Then, just as quickly, the original melody line returns and meanders again in the pastoral. Led by a clarinet and a few other woodwinds and punctuated by a few quick strokes of the violinists' bow, the mood of the song shifts again to an upwelling of joy and lofty ambition. For Richard Wagner, "the Symphony is the Apotheosis of the Dance itself: it is Dance in its highest aspect, the loftiest deed of bodily motion, incorporated into an ideal mold of tone."[16] The interchanging minor and major keys bring the listener from an introspective melancholia to a joyful communion with the natural world and back again. Trading melodies between the first and second violins and among the string and woodwind sections is an excellent example of how investigators and subjects can exchange voices and viewpoints within the confines of the research enterprise. Beyond its capacity for seamlessly shifting moods and tones, Beethoven's orchestration provides a model for the kind of ethical improvisation mentioned in a later section of this chapter.

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[15] Bruce Wilshire, "The Body, Music, and Healing," in *The Handbook of Phenomenology and Medicine* ed. S. Kay Toombs (Dordrecht, Netherlands: Kluwer Academic Publishers, 2001), 224.

[16] Christopher H. Gibbs, "Notes on Beethoven's Seventh Symphony," *NPR Music*, last modified June 13, 2006, http://www.npr.org/templates/story/story.php?storyId=5481664.

Jazz also has the capacity to shift moods from quiet introspection and sense of humility to a free flowing self-confidence and exuberant lust for life. The solitary piano that begins Miles Davis's "So What?" is soon joined by the tiptoeing upright bass. The melody is then transferred from the piano to the bass and the two begin to converse, with the bass leaving space for the piano to respond. Slowly the percussion section slides in with a few taps of the ride cymbal. Then, seemingly from out of nowhere, Davis's trumpet bursts onto the scene with bright tones that announce themselves as the transcendental moment of the birth of the cool. In these transcendental or epiphanic moments, the mood of the listener shifts. Though this is an affective shift, it is also an alteration in the Heideggerean sense of attunement to the world. As illustrated by the renewed vigor felt after a long work out or a successful run, through the body one's world is transformed from an imposing obstacle or source of resistance to a world of concernful living. Through the imagery of jazz and other forms of art, the body is revealed as a dynamic organism that is sensitive to shifts in tone and mood. It is this dynamism and sensitivity that forms one's sense of body schema or style.

In his book, *Intoxicated By My Illness and Other Writings on Life and Death*, Anatole Broyard speaks of developing a style of living and dying.[17] Like the idea of a body schema mentioned above, the body develops its own habits of movement, posture, and bearing that convey a sense of how it fits within the world. For example, the body of a day laborer is generally lean and muscular. The arms and shoulders are well developed. Depending on the kind of labor, the length of employment, and other features of the life story of the individual, his posture may be stooped or ramrod straight. The latter often

[17] Anatole Broyard, *Intoxicated By My Illness and Other Writings on Life and Death* (New York, NY: Ballantine Books, 1992).

indicates military training or an athletic background. The stooped shoulders and soft hands of the scholar are also indicators of a particular body style. Like the movements of a symphony, one's body style changes over time, though it often retains themes from the early years of one's life. In Broyard's case, he consciously chose to display a body style that demonstrated the radiance of insight that his illness had given him. In turn, he chose a physician whose sense of style most carefully fit the disease for which Broyard was seeking treatment.

Within musical nomenclature, the notion of a style of music is expressed as a genre. Although many artists are reticent to categorize themselves within a particular genre, blues artists like B. B. King, John Lee Hooker, and Mississippi John Hurt have commented upon the meaning of the genre as part of the lyrics of their songs. They heavily identify with the deeper symbolic meaning of their music and explore its roots in Southern history and African-American oral storytelling traditions. Other musicians often take pride in their ability to cross-pollinate from radically different genres. So-called experimental bands are able to mix rhythms, instrumentation, and melodies from "pop, swing, rockabilly, country & western, bossa nova, Hawaiian and Middle Eastern music, jazz, Zappa-esque doo wop, arty funk, post-rock, space-age pop, spaghetti-Western music, warped circus melodies, and even dramatic pseudo-new age, plus just a smidgen of heavy metal."[18] Mixing and matching genres in music demonstrate the fluidity of this art form as well as the fluidity of the body in its ability to adopt different body styles. Adapting to illness is another feature of the lived experience that has a deep connection to music.

[18] Steve Huey, review of *California*, by Mr. Bungle, Warner Brothers *Allmusic.com by Rovi*, July 13, 1999, http://www.allmusic.com/album/california-mw0000667688.

Although there are many examples of the healing power of music, Oliver Sacks's autobiographical account of his recovery from a serious leg injury is a particularly vivid account of this power. On his path to recovery, Sacks undergoes a series of transformations wherein his body becomes an object that impedes his projects in the world. He vividly recounts several episodes of uncanniness, which were both frightening and thought provoking. On these occasions, he felt like his leg did not belong to him and lost all proprioceptive sense of its location. Only after listening to Felix Mendelsohn's Violin Concerto, does Sacks begin to recover some sense of self. The concerto serves both to thematize his suffering and to consolidate the disorder of his neural functioning as a species of impaired bodily intentionality. As a re-animator, music serves to bring order, beauty, and complexity into Sacks's inner world. The lush violin arrangement and soaring melody rejuvenates him and pulls him from the abysmally silent world in which he had been dwelling. As he listens, he hopes that his muscles will recognize the rhythm and recall their "forgotten motor melody."[19] As the music courses through him, he speaks of finding something he "had been panting and thirsting for, something that [he] had been seeking more and more frenziedly with each passing day, but which had eluded [him] ..."[20] In fact, music not only buoys his spirits, but also seems to synchronize the spasticity and spontaneity of the nerves in his leg. Given this extraordinary power to heal, music seems well-positioned to join the set of rhetorical devices that may be used to develop an ethics of reciprocity, recognition and respect.

[19] Oliver Sacks, *A Leg to Stand On* (New York, NY: Simon and Schuster Inc, 1984), 94.
[20] Ibid.

ENCOUNTERING THE OTHER

These reflections on the metaphorical linkages between music and embodiment provide the rhetorical framework necessary for developing an ethics of research that is grounded in respect for the body of the Other. Under the musical metaphor, each subjects' body has its own song, which requires an attuned ear to appreciate. Instead of using their senses simply to collect data about the world, an ethics of improvisation asks investigators to find the root of moral responsibility in an aesthetic attunement to the body of the Other. In Robert Coles's phrase, investigators should work to develop a "lyrical, swinging style of empathy."[21] In order to do so, investigators must learn to approach the body in a different way. By approaching subjects as fellow collaborators in the improvisational work of medical research, investigators will learn to recognize their voices within the symphony of life and discover their value. To ask investigators to improvise their ethical responsiveness to the Other and iteratively adjust it according to how the trial progresses should not seem too burdensome a request since improvisation and creativity are already a part of the scientific method.

As suggested above, the face-to-face encounter with the body of the Other is the center of the investigator's moral universe. In order to describe the encounter with the Other, one must first consider how this encounter is possible. First, this encounter involves one's entire self. The presence of the Other is simultaneously sensed, felt, and posited. From a cognitive perspective, to encounter the Other there must already be a space within consciousness for the perception and reception of alterity. From Husserl's work with the subjectivity of experience, one can describe this space as a "pre-reflective

[21] Robert Coles, *The Call of Stories: Teaching and the Moral Imagination* (Boston, MA: Houghton Mifflin, 1989), 72.

passivity in consciousness that precedes the reflective intentional act."[22] The space left for the Other within consciousness is a kind of yielding or intentional receptiveness to the presence of objects and other persons. Perceiving the face of the Other is a conscious experience of an object that precedes reflection upon it. This cognitive receptivity to the idea of the Other as the anticipation of a sense experience of the visage of the Other allows for the awakening of the moral sense catalyzed by an encounter with the face of the Other.

As a felt presence, the moment before the encounter with the face is conditioned by a "vulnerability for the other person that is straightaway irreducible to knowledge."[23] Described as a vulnerability, this affective receptivity subtends the Husserlian categories mentioned above. Like an emotional reflex, it is affectively realized and involuntarily experienced. In Per Nortvedt's term intercorporeal sensitivity and receptivity manifest themselves as an "upheaval."[24] Recognition of the face of the Other arises as an upheaval or as upwelling of the self as it comes into contact with alterity. At the level of the body, metaphorically speaking, one senses the Other as if in a dark forest. The search for the Other is felt at the level of the body as wilderness. At the level of the primordial body, the body of the Other is sensed but not named. Though it may be anticipated at a visceral level, its actual presence is still surprising. Though it is an event that is anticipated and one that occurs on a regular basis, the encounter with the body of the Other still pulls the self out of reverie and brings it to attention. The body awakens, listening for the song of the Other.

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[22] Per Nortvedt, ""Subjectivity and Vulnerability: Reflections on the Foundation of Ethical Sensibility," *Nursing Philosophy* 4, no.3 (October 2003): 224.

[23] Ibid., 225.

[24] Ibid., 226.

While knowledge of the Other may seem to be merely subjective and therefore inferior to objective knowledge, it is appreciated as genuine knowledge in the sense that it exists as presence, as immediate apprehension or illumination. Knowledge of the body of the Other is a similar kind of knowledge. Although it may initially be encountered as a body-object or as a face that is always something other, like knowledge of my own body and knowledge of God, it also appears as something "already present with me."[25] It is present in that it is a felt presence. Its essence extends out from its center and touches my world. An ethos that emanates from the Other is empirical in the sense that moral sensibility is drawn "from experience: in that all our knowledge is founded and from that it ultimately derives itself."[26] The moral responsibility for the Other is not simply a matter of rules for action based on reason, but on the grasp of the Other, the appearance of the Other before our senses. The rules come later, when the investigator's gaze upon the Other is diverted and potentially perverted by other aims.

Since the body of the Other is first perceived by the investigator as an object of sight, it is necessary to speak of the imagery of the face of the Other as a central focus of the objectifying gaze. While seeing the Other is often experienced simultaneously with hearing the call of the Other to moral responsibility, the priority that sight and vision have primarily held within the sensorium of scientific study as well as the importance of sight within phenomenology suggests that the encounter with the face of the Other should begin with a discussion of vision and the visage. The eye has a long history as an object of considerable symbolic value. It is "not only symbolic of the self, and expressive of

[25] Sonia Kruks, "Marcel and Merleau-Ponty: Incarnation, Situation and the Problem of History," *Human Studies* 10, no. 2 (Spring 1987): 229.

[26] John Locke, *An Essay Concerning Human Understanding (1689)* (Amherst, NY: Prometheus, 1994), 59.

moods, emotions and dispositions … it is also one note among the many organs of body language."[27] Eyes are external indicators of the internal disposition of the self and the Other. They can be tools of domination or offer the possibility of a vision that glances or glimpses, but does not pierce or invade. As the investigator's eyes settle upon the subject, he "look[s] into the eyes of the Other and see[s] the Other's disposition, mood and soul: the truth about the Other."[28] These truths are provisional, they must be borne out in conversation, but they provide insight into the nature of the subject. Furthermore, by the way in which the investigator's moral vision is framed, he signals to the subject how he will be treated. To see the subject only as an object is to treat him as such. Though the balance of preliminary evidence is against the investigator in this respect, the clinical gaze may be softened if he is aware that "by the glance which reveals the other, one discloses himself."[29] Reflecting upon the initial judgments one makes about the Other is an opportunity to alter the gaze, to deepen one's looking.

Making one's looking deep and broad reveals the essence of the face of the Other. Levinas notes that "because it is the presence of exteriority the face never becomes an image or an intuition" as a way of saying that the person is more than the face they present or the object that they may appear to be at first glance.[30] Broadening and deepening one's vision of the subject allows the investigator time to see "the infinity of the other, [as] a destituteness, a presence of the third party (that is, of the whole of humanity which looks at us)."[31] Seeking out the destituteness of the Other is a way of returning to consider our own unhomelikeness in the world. Seeing the Other as destitute

[27] Anthony Synnott, *The Body Social* (New York, NY: Taylor & Francis, 1993), 224.
[28] Ibid., 225.
[29] Ibid., 226.
[30] Levinas, 297.
[31] Ibid., 213.

means finding a common sense of deprivation that is at the heart of the human condition. Destitution is unhomelikeness. The face has no home in my world, in my interiority, nor do I have a home in his. We are both separate beings, but can welcome each other through the encounter with one another. In Levinas's description, the face of the Other, no matter where it comes from, "has the face of the poor, the stranger, the widow, and the orphan, and, at the same time, of the master called to invest and justify my freedom."[32] In Levinas's view, the Other occupies an ambiguous position. He is the source of my moral obligation because of his alterity and his destituteness. His destituteness is also the source of his strength. The power of his presence commands me not to harm him, to reflect on what it is that I owe him without attempting to comprehend him in his entirety and thereby wrong him.

In the sequence of the face-to-face encounter, vision precedes speech and presents the Other as both similar to me and radically different. Speech identifies the call to moral responsibility and my response. Our dialogue is constructed by the call, which maintains my distance from the Other. Language separates us through the multiplicity of interpretations, miscommunication, error, etc. Vision precedes speech because it identifies the Other as a fellow body-subject. This identification establishing our general proximity to one another. As Levinas notes, "the interlocutor can have no place in an inwardness; he is forever outside."[33] I value the Other not only because of his kinship but also because of his alterity. At the same time, my image of him limits him by transforming him into an object of my gaze. The only alternative to avoiding using the gaze to internalize him is to open myself up to him as an interlocutor.

[32] Ibid., 251.
[33] Ibid., 295.

Part of the rhetorical power of the metaphor of musical body is its ability to place Foucault's clinical gaze and Sartre's Look into conversation with Levinas's understanding of the face and Merleau-Ponty's sense of uncovering the "flesh of the world"[34] that binds each to each through vision. Seeing the face of the Other offers insight into how ocular power represents the possibility of both dominance and cooperation. To approach the face of the Other is to reveal the tension between a series of dichotomies: the clinical gaze/ aesthetic gaze, subject/object, and the epistemic/ moral.

Levinas's description of the face of the Other is central to the theory of respect for persons that I wish to outline in this chapter. Going beyond the mere depiction of any particular human face, Levinas describes the *visage* of the Other as "the way in which the other presents himself, exceeding *the idea of the other in me*."[35] From the actual physical encounter of the face-to-face, the idea of the Other expands, "destroys and overflows the plastic image it leaves me."[36] Encountered as a face, the Other is a teacher of infinity. Placed in relation to the dominating force of scientific thought which seeks to systematize knowledge, the face of the Other resists power. Presenting itself as a glimpse of infinity in bounded space, the face of the research subject transforms the investigator into the role of a student.

The foundation of a moral life in general, not just moral responsibility, is to be found in the encounter with the face. Although it begins with a sensible impression of the Other, "the relation with the Other alone introduces a dimension of transcendence, and leads us to a relation totally different from experience in the sensible sense of the term."[37]

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[34] Merleau-Ponty, *The Visible and the Invisible*, 136.
[35] Levinas, 50.
[36] Ibid., 51.
[37] Ibid., 193.

Gazing upon the face of the Other is a moment of unhomelikeness, where the self is called to attention, called out of reverie. As revealed in a vision of the Other, "the ethical relationship which subtends discourse is not a species of consciousness whose ray emanates from the I; it puts the I in question."[38] It does so because it overwhelms me; it overflows my consciousness. An encounter with the other retains some of the same, in the sense that it is an exchange, not a confrontation. Establishing what Richard Zaner calls "vivid presence" is one way of recognizing the Other in the shared moral moments which take place in the clinical space. Vivid co-presence is "a relationship in which persons are present to each other and at the same time aware of their shared presence."[39] Zaner refers to this fundamental way of relating to the Other as making music with the Other.[40] It is an invitation, but not an invitation to a relationship of dominance and resistance or passivity. This invitation is primordial, as it arises prior to inscription or documentation of the moral obligations outlined as part of the research enterprise. In fact, "the manifestation of the face is already discourse."[41] It is a presence which inherently expresses meaning, a meaning that extends deeper than a consent form.

Under the current regime of research ethics, the face-to-face encounter that is driven by speech, hearing and listening, and touching is subsumed underneath the inscription of the moral universe of investigator and subject in a document. In everyday experience as well as in the clinic, sound is supplanted by sight. The clinical gaze is inscribed in the spaces of the clinic and laboratory and reinforced by a document that

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[38] Ibid., 195.

[39] Anne H. Bishop and John R. Scudder Jr., *Nursing Ethics: Therapeutic Caring Presence* (Boston, MA: Jones and Bartlett, 1996), 59.

[40] Richard Zaner, *The Context of Self: A Phenomenological Inquiry Using Medicine as a Clue* (Athens, OH: Ohio University Press, 1981), 236.

[41] Levinas, 66.

codifies the moral obligations of the investigator by appeals to sight. If a dispute arises, the investigator and subject return to the consent form and visually identify their signatures as testimony. The form serves as witness to the disclosure of information and the acknowledgment of rights and responsibilities, but it cannot speak to what occurs after this document has been signed. Instead, the subject is left to his own devices with only the walls of the clinic and the ears of the research team to record the dialogue between science and humanity.

Although it is often neglected in some mainstream analyses of clinical and research ethics consultations, the importance of listening within the confines of dialogical relationship cannot be overemphasized. Through his research on French airline employees, an otolaryngologist named Alfred Tomatis discovered that "sound is the unique sense that gives continuity to our lives; it is the fundamental building block of learning and communication."[42] Hearing is itself a more inclusive sense than sight. It does not depend on the orientation of the body in order to take in information about the world.[43] Before the inner spaces of the body could be safely seen with instruments that invade but do not permanently harm, physicians were dependent on hearing to gauge the health of the body. Indeed, the possibility of intersubjectivity as a kind of nonthreatening, infinite continuity between persons is based not simply on recognizing the face of the Other. Instead, hearing the call of the Other in a metaphorical and literal sense is the root of the moral relationship between the investigator and the subject. Though sight initiates the moral obligation by providing a glimpse of the radical alterity, sacredness, and

[42] Updike, 297.
[43] Wilshire, 220.

infinity of the Other, the subsuming of the investigator's scientific obligations underneath his duty to respect the body of the Other is revealed in the call.

Although it sounds like the call of the face would be a linguistic entreaty, it is not simply a vocal expression but the body presented in its nakedness, in its vulnerability. The nakedness and destitution first glimpsed in the visage of the Other presents a moral obligation prior to language. As Levinas describes this encounter,

> The being that expresses itself imposes itself, but does so precisely by appealing to me with its destitution and nudity—its hunger—without my being able to be deaf to that appeal. Thus in expression the being that imposes itself does not limit but promotes my freedom, by arousing my goodness.[44]

What is heard when the body of the Other speaks is this imposition, what Levinas refers to elsewhere as the prohibition against murder. The body of the Other presents itself in its frailty and commands mercy. It speaks with the voice of all of humanity to demand justice. It appeals to our common metaphysical hunger expressed as the Desire for the Other. Before discourse there is the presentation of nudity, vulnerability, and a common Desire. Listening for the call of the Other acknowledges "our existence as sonorous beings for others and for ourselves"[45] When the body of the Other speaks, the investigator must be prepared to listen not simply with an objective ear that seeks out the sounds of science but also with an ear for the subject that speaks through the body. In anthropologist Thomas Csordas's view, "the filaments of intentionality that crisscross between and among us humans take sensuous form in language. Speaking is a kind of

[44] Levinas, 200.
[45] Merleau-Ponty, *The Visible and the Invisible*, 155.

sonorous touching: language is tissue in the flesh of the world."[46] One needs simply to substitute "music" for "language" to get a sense of how essential vocal and musical communication is to intercorporeality and intersubjectivity. It is not just the act of hearing, but the response to the musical body that "announces the ethical inviolability of the Other."[47]

Preceding and immediately following the call of the Other there is silence while the self attends to the call and formulates a response. In music, silence provides a guide for the ear to distinguish between notes. It establishes rhythm and tempo by demarcating the structure of time within a musical piece. In most modern rock music, the downbeat is used as a measurement of the time signature in any given bar, yet it stands in opposition to the upbeat, which is normally silent. In symphonic music, entire sections of the orchestra are often silent. If they come in too early, they disrupt the flow of the movement. Silence in between notes is as important as the sound. In music as in life, absence is as important as presence. Each of these is not merely an idea, but is experienced phenomenologically. Listening is a kind of knowing that requires the self to be attuned to both presence and absence.

Despite French surgeon René Leriche's claim that health is "life lived in the silence of the organs," healthy bodies are actually determined by their sounds.[48] For example, physicians listen for abnormalities in the lungs and check for expected bowel sounds. EKG's are a prime example of how sound waves indicate health or illness and where silence in the wrong places can be an indication of pathology. As part of the lived

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[46] Thomas Csordas, "Intersubjectivity and Intercorporeality," *Subjectivity* 22, no.1 (May 2008): 118.

[47] Levinas, 195.

[48] Georges Canguilhem, *On the Normal and the Pathological*, trans. Carolyn R Fawcett (Hingham, MA: D. Reidel Publishing, 1978), 46.

experience, if sounds are expected, as in when one loses his voice due to laryngitis, the experience can be frightening. Likewise, when one expects silence, as in when exiting an empty concert hall after a show, and instead finds a ringing in the ears, the lifeworld is disrupted. Silence can also be a source of relaxation and even necessary for concentration. In music, time structures "are built on silence, they can permit anything at all to happen within them."[49] It is also silence that indicates a shortcoming in the ethical responsiveness of the investigator if he does not allow the body of the subject to speak. Silence in this form can be both a sign of power and a warning.

Ethics as a real-life improvisation is built on silence as well. The silence between bodies and the silence between two understandings of the body that conflict should not be seen as an abyss from which nothing may arise, but as the materials for dialogue. Silence is a vacuum into which investigators and subjects can enter into a responsive relationship. When one player has sounded out his melody, his partner has time to reflect upon the call before giving a response. Were there no silent spaces, there could be no space or time for reflection. Giving time for reflection and opening the space through silence is integral to a dialogical relationship between investigators and subjects. Silence in this sense is an emptiness of the will, where even the echoes of the power disparity between investigator and subject have dissipated.[50] Through an act of generosity the conversation may emerge out of the pregnancy of this silence.

Answering the call of the other is a commitment to the dialogue between body-subjects. It requires an "initial act of generosity, a giving of my world to him with all its

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[49] James Pritchett, "What Silence Taught John Cage: The Story of 4'33"" (2009) http://www.rosewhitemusic.com/cage/texts/WhatSilenceTaughtCage.html.

[50] Frances Dyson, "The Ear that Would Hear Sounds in Themselves; John Cage 1935-1965" in *Wireless Imagination; Sound, Radio, and the Avant-garde*, eds. Douglas Kahn and Gregory Whitehead (Cambridge, MA: MIT Press, 1992), 390.

dubious assumptions and arbitrary features."[51] Two features are important here. First, responsibility is the foundation of moral obligation, an assumption that guides our conduct towards the other. It begins with the encounter, but is consummated in communication. Communication in the clinical research encounter is presently structured by the acts of seeking and granting permission. It is a sacred communication where a gift is bestowed, with corresponding obligations. This gift is the offering of one's world to the other. Recognizing the call of the Other and responding with a gift is to "come to [the Other] across the world of possessed things, but at the same time to establish, by gift, community and universality."[52] Here "universality" is not the totalizing effect of absorbing another into one's own world, but in the sense of the possibility of a common world or shared meanings. In the encounter, "the generality of the word institutes a common world. The ethical event at the basis of generalization is the underlying intention of language."[53] The ethical event Levinas refers to is the prohibition against murder, but may also be thought of as any act that harms the Other or neglects one's responsibilities.

Second, taking care to accept responsibility for the clarity of communication is essential to showing respect for the other, but is not the foundation of respect. Generosity is the foundation of the moral relationship between the investigator and the subject. Each is asked to offer his world to the other. Participation in the scientific mode of being in the world is offered by the investigator while the subject offers the investigator an opportunity to participate in his world. *Generosity*, by definition, is the spontaneous giving of oneself, of more than is asked. It is synonymous with liberality.

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[51] John Wild "Introduction" in Emmanuel Levinas *Totality and Infinity: An Essay on Exteriority*, trans. Alphonso Lingis (Pittsburgh, PA: Duquesne University Press, 1969), 14.

[52] Levinas, 76.

[53] Ibid., 173.

In response to the call of the Other, investigators may determine that the call is actually a request to make space for *sermo*.[54] Levinas seems to have had this ideal in mind when he referred to the conversation as "not the unfolding of a prefabricated internal logic, but the constitution of truth in a struggle between thinkers, with all the risks of freedom."[55] If one considers this as an invitation to *sermo*, then it is also a space where the interlocutors are equals, which is supported by the moral obligation of the face-to-face encounter as well as the generosity of the Other and the I. Furthermore, to enter into *sermo* is to acknowledge that neither interlocutor has a monopoly on truth. Indeed, the point of *sermo* is to discuss freely and openly those controversial issues that may otherwise give rise to unwise and intemperate speech. How the body should be viewed and treated is one example of an appropriate topic.

As noted above, music and speech differ significantly from language as inscription. The shift from face-to-face communication to the consent form as a proxy for the moral obligations established by the face-to-face relationship interferes with and dilutes the moral foundation of the research enterprise. Instead, research ethics is currently dominated by the inscription of the roles of each person as documented in the consent form and in the institutional review board's evaluation of the protocol. The face-to-face relationship should not be built solely on a contractual obligation prescribed by an institutional foundation that supports the investigator whereby the institutional affiliation lurks in the background as a third party to enforce the provisions of the contractual obligation. If this were the only support for the relationship between investigator and subject, then the asymmetry of the power relations would support the ethical obligations

[54] Gary Remer, *Humanism and the Rhetoric of Toleration* (University Park, PA: Pennsylvania State University Press, 1996), 94-97.

[55] Levinas, 73.

of the investigator and he would take them seriously only insofar as he fears retribution from the institution. Instead, this foundation must arise solely from an interpersonal relationship established by a much deeper and primordial obligation to the Other. In a relationship of bodily recognition and empathy, a foundation for conversation as the expression of the moral relationship between two persons is established. Without reciprocity there is no ground for dialogue. If placed solely within the purview of the institution where the institution stands in as third party and not the whole of humanity, there is no discourse as there are no interlocutors. Institutions cannot be interlocutors for they do not exist as subjects driven by Desire for the Other. The institutional power spoken of here is relayed to the subject via the choice of metaphors investigators use to describe the body. Furthermore, this pressure creates a discourse that dehumanizes the most sacred of human senses: the sense of touch.

When physicians and nurses touch the skin of their patients, the aim is to diagnose and treat disease. For a patient that is suffering, the warm and friendly pat on the back or clasp of the hand by an attentive nurse or physician can be reassuring. However, the investigator seeks permission to touch the skin in order to learn something about the body or to use what lies beneath in order to test an unproven intervention. The change in focus and rationale is significant. Physicians cross the threshold between "two modes of being" as priests who have been bidden to enter sacred ground.[56] It is not at all clear that investigators are aware of the significance of the experiences of touching and being touched. While they have been granted access to the sacred spaces of the body, they bring with them a form of tactile sensibility that is rooted in the clinical gaze.

[56] Eliade, 25.

The clinical gaze turns the body into the anatomico-physiological body through a palpation that dissects. Metaphors that focus the gaze of the investigator on the organic structures of the body and ignore the symbolic value of the senses, skin, and other organs seek to control the body through the power of touch. The hand that plunges the needle through the skin and into a healthy thigh to take a biopsy as a measurement of the effectiveness of a drug seeks not cure or comfort but knowledge. The eye that guides the hand does not grasp for the person, but grabs and retracts the skin in order to gaze deeper. Sensitivity to how the gaze guides the hand is a necessary component of the ethics of the body. It is here that a new metaphorics of touch may be necessary.

Touching the surface of another person's body closes the distance between the self and the Other in a manner not considered by Levinas or Sartre. Under the metaphor of the musical body, intercorporeality offers the possibility of intersubjectivity through the unity of the visible and the tactile. Instead of approaching the body of the research subject as a scientific object, investigators learn to feel the music of the subject's body. Aesthetic considerations of form, function, and flow drawn from musical appreciation introduce the investigator to the beauty of the body. From an aesthetic appreciation of the body, investigators discover the intrinsic value of the lived experience of the body-subject. Through a metaphorics of touch based in aesthetics, a new kind of tactile sensibility emerges as a deference in the midst of a desecration. Investigators learn to grasp the potentialities of the body-subject without limiting the value of the body to the merely instrumental. This new metaphorics of touch captures the sense of body-subjects "as embodied selves who are not just interdependent but whose morphology is without

divisive boundaries."[57] A broader definition of flesh as more than the corporeal material covering of the body emerges wherein each person is connected via the sinews and ligaments of intercorporeality.

The investigator-subject relationship as described above is transcendent due to its basis in bodily intentionality as a pointing towards the Other. Offering oneself through language, but not becoming the Other or becoming something other than the I is an act of transcendence. In going beyond the normal confines of the investigator-subject relationship, these interlocutors find a common ground in the realm "*beyond* the distinction of objectivity and subjectivity."[58] Although they meet under the gaze of an institution that represents the pursuit of knowledge wherein each party is valuable only insofar as they are able to produce knowledge, investigators and subjects have the opportunity to develop a relation of "with" as in "with me" and "with him" wherein the Other is recognizable as a being that is intersubjectively constituted. Within the clinical environment, investigators and subjects develop a relationship of "*oblique* interdependence."[59] This interdependence is developed through a style of ethical communication that is improvisational.

As an essential part of jazz music, improvisation is dependent on a relationship of trust, generosity, reciprocity and respect. Musicians who wish to improvise together must be well-versed in the baseline melody. They must have formed a connection to each other's musicianship through experience and study of musical structure prior to the improvisational work they wish to perform. When each player is in sync with his

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[57] Margrit Shildrick, "Beyond the Body of Bioethics: Challenging the Conventions," in *Ethics of the Body: Postconventional Challenges*, eds. Margrit Shildrick and Roxanne Mykituik (Cambridge, MA: MIT Press, 2005), 8.

[58] Kruks, 229.

[59] Sartre, 246.

"interlocutor" and both have found the rhythm, tempo, and key that fits their moods, it is often said that they have found the "groove." This is an iterative process that requires each player to "listen critically to his fellow players and to himself … His task is to find the correct note, phrasing, dynamics and register on his instrument at a moment's notice."[60] Finding the right note to strike in order to convey a sense of openness and trust is essential for the development of a healthy relationship. While the consent form and the protocol provide a baseline or "bass line" from which a harmonious relationship may emerge, it is up to the players to find the groove.

Ethical improvisation, like jazz improvisation, is "truly the means by which commitments are redefined and refocused—sometimes, but only sometimes, by choice."[61] These commitments are laid out in the consent form, but they truly resonate only at the level of the face-to-face. As a kind of moral perfectionism, ethical improvisation demands self-reflection and the commitment to "speaking and acting true to oneself, combined with a thoroughgoing dissatisfaction with oneself as one now stands."[62] Of course, to demand moral perfectionism of investigators is perhaps to overreach the boundaries of one's role as a medical humanist. Nonetheless, the demand for moral perfectionism might be considered as part of the professional identity of the investigator and therefore would be a legitimate claim for one's peers and society in general to make. However, judgments about how dissatisfied investigators should be with themselves should be considered relevant only in retrospect. That is to say, the historical episodes recounted in the previous chapters should remind investigators how far the field

[60] Lukas Foss, "Improvisation versus Composition," *Musical Times* 101, no. 1436 (October 1962): 685.

[61] Ibid.

[62] William Day, "Knowing as Instancing: Jazz Improvisation and Moral Perfectionism," *The Journal of Aesthetics and Art Criticism* 58, no.2 (Spring 2000): 99.

of medical research can fall when it is not guided by professionals committed to self-reflection and self-criticism.

The heart of jazz improvisation lies in the reevaluation of one's "habitual responses to the world."[63] In the research enterprise, this translates into the habit of adhering to the regulations guiding human subjects research as simply another checklist to be filled out. In the style of jazz improvisation, the regulations form the baseline for ethical conduct, but in order to fully respect persons investigators must improvise. Successful improvisation is realized as the "result of the improviser's full awareness of his place and presence, of his working through his conventional responses."[64] Improvisational ethics requires that investigators move beyond the regulations to see moral relationships that define the scientific research enterprise as part of the "lived activity" of medical research.[65]

[63] Ibid., 99.
[64] Ibid., 100.
[65] Ibid., 102.

Interlude: Reevaluating the Metaphors of Embodiment

In this interlude between the discussion of the metaphors of embodiment and the medical humanities curriculum I will discuss in Chapter 5, I outline a brief critical assessment of the epistemic and normative content of the metaphors discussed in the previous chapters. This assessment will result in a systematic analysis of the strengths and weaknesses of each metaphor. In so doing, I will show how some of these metaphors might be incorporated into the research ethics curriculum and why others should be discarded.

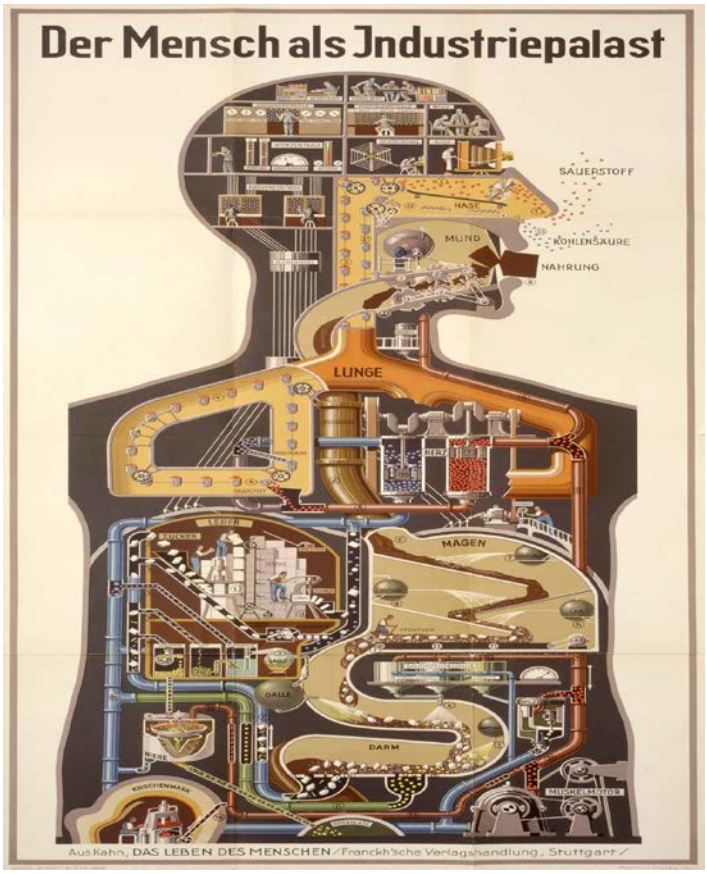
Each of the metaphors discussed in the previous chapters has epistemic and normative content. Some enable investigators to recognize the intrinsic value of body-subjects, while others cloud their moral vision. In this section, I will briefly summarize the epistemic and normative content of each metaphor, proceeding in the order in which they were described in the second, third, and fourth chapters. By "content" I mean the rhetorical power of each metaphor to organize ways of thinking about and investigating the body and embodiment. Then I will provide arguments either for their incorporation within the moral vision of investigators or their removal from the discourse of medical research.

As mentioned in Chapter 2, the *mechanical metaphor* has vast epistemic potential in the sense that it helps to organize scientific ways of thinking about and investigating the body. As a guiding metaphor of medical research, it has proven to be quite helpful for establishing some of the foundational axioms regarding the structure and functioning of the body. However, it is also epistemically deficient in that numerous aspects of the body

and embodiment seem to defy explanation through the laws of mechanics. Long recognized as a major threat to the viability of the metaphor is the problem of the compatibility of mind and brain. Explaining mental states in the mechanical terms used to describe brain states often either devolves into explaining away the mind as an organizing principle of human experience or inadequately accounts for the complexity of mental functions. Furthermore, while neuroscience has made great strides in sorting out which areas of the brain seem to activate in response to certain stimuli, there are still inherent difficulties in establishing direct causal links between the two phenomena. In addition, scientific literature has historically discounted subjective experience. Investigators have been unwilling or unable to see the value in recording subjective impressions of experimental procedures that do not address the research question within the defined parameters of scientific discourse. Thus, it seems that the mechanical metaphor of the body is limited in scope and application, in some cases to the detriment of scientific investigations. While it would be unwise to sacrifice the epistemic potential of this metaphor, it should be couched as one of several viable metaphors that have explanatory power. In order for the mechanical metaphor to maintain a level of explanatory power that is epistemically helpful but not morally pernicious, it must be integrated into an aesthetic understanding of the body, not required to unilaterally explain all aspects of embodiment.

As an alternative to the objectifying potential of the mechanical metaphor, one could acknowledge its explanatory power without claiming that it is the only proper way of understanding the body. One way to do that is to show how it is possible to see the machine body through an aesthetic lens. Consider gynecologist and illustrator Fritz

Kahn's "Der Mensch als Industriepalast (1926)" (Fig. 6). Although it appears that most of the respiratory and circulatory functions are carried out through a series of mechanical and hydraulic processes, other integral functions are carried out by miniscule human figures. Seated figures above the heading "Reason" in the upper portion of the diagram seem engaged in a contentious debate while next door the "Understanding" reads from a text. Underneath "Reason" the "Will" seems divided as the three figures appear uninterested in each other. Kahn's illustration explores the integration of the flesh and the machine by incorporating human figures as monitors of the central nervous system. The rest of the functions at the top of the diagram are controlled by switchboards or by professional-looking figures holding clipboards and monitoring switches. What is of particular interest among these figures is the worker in the center attached to a cube or web-shaped apparatus, apparently meant to represent the organ of hearing. The symbolic value of the web seems to point to the larger interconnections among the various systems through a series of pipes and wires.



Although Kahn's image is a brilliant and highly technical analogy of the body as machine, its exploration of both flesh and machine also invites contemplation of the ambiguity of embodiment. Viewed through an aesthetic lens, the machine body is seen as a part of a broader picture of embodiment as embedded in a network of systems. While some features of the body may be explicable in the language of mechanics, there are

other features that are explicable only if the body is seen as an emergent, organic totality that is greater than the sum of its parts.

While on the whole the *industrial metaphor* holds an even more central position in the epistemology of medical research than the mechanical metaphor, its epistemic power is not without serious ethical consequences. The acquisition, compilation, quantification, and analysis of biometric data are at the heart of medical research. Processing this data through statistical methods often results in persons being reduced to mere points on a graph. Yet, lived bodies need not be reduced to statistical bodies. There are means at the disposal of the investigator to find space for both the lived experience and the necessary task of compiling data about the body. Careful attention to how statistical normalization leads to the lack of diversity in the subject population is an important first step. Although this process has more to do with the construction of inclusion and exclusion criteria than it does the maintenance of the investigator-subject relationship during the trial, both concern the power relations between the investigator and subject. Unjustifiably denying access to trials based on the need to standardize the body types that are included is both an issue of social justice and a problem of showing respect for persons. Unfairly excluding individuals from research solely based on their race, gender, or other characteristics that do not affect their health status may be perceived as an affront to personhood. In general, the industrial metaphor seeks to extract instrumental value from individual bodies while ignoring the value of individual subjects.

The isolation of the individual within the machinery of the clinical research enterprise often leads to the alienation of individuals from their peer groups. Placed in a confined space that is built around the reification of reductionism, subjects often feel as

though they are simply anonymous bodies. Treating persons as mere cogs in a vast industrial machine dehumanizes them. However, the ethical implications of the industrial metaphor may be mitigated by refocusing the attention of investigators towards the intrinsic value of individual subjects. Making subjects feel welcome and as though their subjective knowledge of their own embodied experience is important is a simple matter of first recognizing them as partners in the research enterprise. Instead of seeing subjects as machines for the production of data, investigators should learn to see them as body-subjects who play a vital role in orchestrating the symphony of science. Bodies in concert with one another are far more likely to share valuable information about the experience of embodiment than those that are discordant.

The ethical implications of the industrial metaphor place it in conflict with the normative obligation to respect persons. Investigators who have been persuaded that the proper way to see persons is as mere factories of knowledge have subsequently been tempted to place them outside the realm of moral responsibility. Quantifying the body is always ethically problematic as it is inherently reductive. Nonetheless, replacing this foundational image with the metaphor of the body as music allows for the quantification of the body without implying that the body merely serves as a data point. The image of bodies as members of an orchestral body intertwines with the related image of the anatomico-physiological gaze as a notational device that guides exploration of the body but does not fully determine its relationship to the self, moods, tones, rhythms, etc.

As mentioned in Chapter 2, the *agricultural metaphor* is almost entirely without merit. Its epistemic power is reductive to such a degree that it seems irredeemable. Moreover, the idea of the body as a crop to be harvested does not provide any guidance

on how to study the body once it has been harvested. It simply indicates that bodies may be used as disease models, but does not provide any indication of how they may serve such a purpose beyond the understanding that they are organic, grow, and reproduce. This epistemology is simplistic and does not serve to drive any serious research programs. By way of comparison, the mechanical and industrial metaphors give some indication of how one might study the human body, that is, by studying its "mechanical" features or quantifying its outputs and inputs. The agricultural metaphor identifies the body as a biological object of study but does not elaborate on the nature of the body as lived or even as a working object of science.

The ethical issues with the agricultural metaphor are numerous. While the idea of human body parts—tissues, blood, plasma, etc.—being sold commercially or given for transplantation in the bodies of others seems to have become more widely accepted, the metaphysical problems with commodification of the body remain. If human beings are nothing but walking commodities whose bodies may be exploited for the gain of others, then these practices are not unethical. However, if there is something more to embodiment than the warehousing of goods prior to their sale then the practices described in Chapter 2 should be seen as ethically problematic. Furthermore, the metaphor of harvesting knowledge is inherently a discursive strategy that places knowledge above being and the knower above the object of epistemic desire. As a relationship that is already driven by an asymmetrical distribution of power and knowledge, investigators and subjects need not be further separated by an ideology that dehumanizes and exacerbates these inequalities. Although German philosopher Friedrich Schiller argued that the "cultivation of aesthetic sensibility, and of aesthetic and artistic experience more

generally, is understood in terms of acting as a palliative" for the degradation of humanity as a mere economic instrument, aesthetic sensibility would face serious challenges when placed against this metaphorical background.[66] As such, this metaphor has no place in the moral vision of investigators.

As an alternative to the rhetoric of reductionism, the *temple body* offers insight into the emergent properties of the body-subject. From its roots as an expression of theological holism, the temple metaphor locates the coextension of spirit, matter, subject and object within the lived experience of the body-subject.[67] Although investigators may reject theological holism, there is no reason to discount a secular version of this theory, especially one that is able to incorporate a scientifically-driven systematic approach to the body as an organic totality. Epistemically speaking, a the notion of holism that emerges from a conception of the body as a systemic whole is of some value as it points to the potential for error in reductive thinking about the body. However, the main appeal of the temple metaphor lies not in its epistemic power, but in its ethical content.

As a response to the industrial metaphor, which places value in the body only insofar as it produces knowledge, the temple metaphor attributes intrinsic value to the body as a product of divine love. Moreover, the temple body is not simply intrinsically valuable, but intrinsically good. However, scientists who believe that their practice is nonreligious may find it difficult to relate to an ethical theory that relies to some extent on the idea of divine love. While this objection is certainly worth considering, ideas like *soma* and *sarx* may be taken out of their religious context and still have meaning. The

[66] Elizabeth Schellenkens, *Aesthetics and Morality* (London, UK: Continuum International Publishing Group, 2007), 111.

[67] This concept was explored in Chapter 3, but is essentially the view that the body is the outward expression of the soul.

idea of flesh as that which binds human beings to each other is a concept that speaks to the intrinsic value of human life. Furthermore, embodiment and subjectivity are the core features of personhood from which the call of the Other emanates. These features are shared by both believers and non-believers. Through the illumination of the architecture of embodiment, this metaphor offers a new way of configuring the boundary between the sacred and profane by using the skin as a symbolic threshold between these two modes of being. Were investigators to see the body as a temple or sanctuary, they would be more respectful of its boundaries. Furthermore, the temple metaphor undermines the industrial and agricultural metaphors by appealing to the worth of the individual as unique and priceless. Were investigators to see subjects as both unique and priceless, they would be more concerned about the potential for exploitation through commodification. They might find other ways to show their appreciation for human subjects' participation than simply providing monetary compensation.

Pedagogically speaking, this metaphor has value in that many of the visual images generated by the anatomists mentioned in earlier chapters utilize the architectural conceit of man as a building engineered by the Divine Architect. Incorporating the history of medical research in the Renaissance into the study of visual images will help investigators understand how scientific images of the body have blurred the line between aesthetic and anatomico-pathological vision. More importantly for the project of cultivating moral vision, the temple metaphor discloses the sacredness of the body of the Other as well as how the bond of embodiment offers an opportunity for intersubjectivity.

The epistemic content of the *American metaphor* is multimodal and seems to be internally inconsistent. The image of the *body as wilderness* calls attention to the

disconnect between scientific and subjective knowledge. In so doing, it reserves a space for the contemplation of the limits of both kinds of knowledge. Use of this metaphor could either encourage investigators to value subjects' experience of embodiment or could result in an exacerbation of the impulse to objectify the body in order to control it. If the body is seen as a wilderness, some investigators would be inclined to tap into the lived experience of the subject in order to help them navigate their way through it. This move, while certainly an improvement as it acknowledges the value of subjective experience, would actually diminish its importance as the native landscape would be replaced by a medical map. Furthermore, incorporating this metaphor might cause investigators to be dissatisfied with their efforts; some might see wilderness and uncertainty as a failure. Subjectivity would continue to be seen as an insufficient guide to knowledge. However, the body as wilderness only captures part of the experience of embodiment. A closer analogue to the lived experience is the *pastoral metaphor*. The pastoral metaphor also has more epistemic power than the wilderness metaphor. Describing the body as a pastoral space allows for it to be seen as a liminal space between control and chaos. The pastoral body is open to exploration by the clinical gaze, but does not allow the gaze to dominate. Instead, it turns to the sublime as a way to acknowledge the limits of the scientific understanding of the body. Furthermore, the third image expressed by the foundational metaphor of the body as America is a primarily scientifically-driven one. Put simply, the *cartographical metaphor* claims the body for science. While this metaphor has explanatory power, its ethical implications are problematic.

The American metaphor is a complex pastiche of images, yet it contains its own self-regulating discursive strategy in that the pastoral metaphor creates a moral space for self-reflection and self-anatomization. Furthermore, the potential for dominance of anatomico-pathological ways of knowing is mitigated by the integration of the scientific and the aesthetic. As a pedagogical strategy, use of the pastoral metaphor opens up investigators to the sublimity of the Romantics as part of the development of aesthetic attunement. As such, the American metaphor is a helpful rhetorical device and should be integrated into the research ethics curriculum described in this chapter. However, it should not be the primary rhetorical device in operation, that honor belongs to the aesthetically-driven metaphor of the body as music.

When compared to the other metaphors discussed above, the metaphor of the *body as music* is clearly superior in both its moral and epistemic content. Although the pastoral metaphor is almost a suitable candidate for a foundational image in which to ground aesthetic attunement, it frames the pursuit of scientific knowledge in opposition to the aesthetic. The tension that this conceptual schema creates is both the pastoral metaphor's greatest strength and its greatest weakness. Unlike the American metaphor in general, the musical metaphor does not place science and aesthetics in conflict, but shows how they may work together to produce knowledge about the body while maintaining respect for persons. Like the pastoral metaphor, the musical metaphor unifies the body-subject and the body-object.

As mentioned in Chapter 4, investigators who subscribe to the musical metaphor see the music of the body as something to decode in order to uncover the structure of its

harmonies and cacophonies.[68] Scientific viewing of the body requires similar skills of interpretation and tolerance for ambiguity, especially as concerns the field of neuroscience and neuroaesthetics. However, investigators traditionally have not valued ambiguity, though they often reluctantly point to ambiguous findings in their written experimental reports. Investigators as a whole are more accustomed to accounting for uncertainty than ambiguity, even though both serve a motivational function in scientific knowledge production. Ambiguous findings are not highly valued in research as part of the institutional pressure to produce clearly positive findings. Nonetheless, the aesthetic perspective is not fully discounted in science, since part of the search for reliable theoretical descriptions involves some sense of scientific beauty and elegance in description.

The musical metaphor is able to hold the clinical gaze, the Look of the Other, and the face of the Other in tension without allowing any of these rhetorical devices to dominate the others. As mentioned above, the musical metaphor taps into the temporal and spatial dynamics of the lived experience. For the purposes of developing aesthetic attunement, it elucidates the central role of body styles as the key to recognizing the subjectivity of the Other. Although the body may be covered in standardized hospital attire, the body style of the Other is always apparent in the face, gestures, and language. The healing power of the musical metaphor is expressed epistemically and ethically through its ability to heal the moral rupture caused by objectification and to remind investigators of their allegiance to broader therapeutic goals.

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[68] A Sánchez Sousa, F Baquero, and C Nombela, "The Making of 'The Genoma Music,'" *Revista Iberoamericana de Micologia.* 22, no. 4 (December 2005):242-8.

While the musical metaphor's epistemic power seems sufficient to unite the discourses of body-subject and body-object, it is the normative content that is of primary concern for the purposes of this dissertation. Under the foundational image of the body as music, the body of each subject is revealed to have its own song, which is its subjectivity and the source of moral obligation. Subjectivity may be discovered through the senses. To grasp the Other is to perceive his subjectivity. Perceiving the Other is also essential to the performance of a musical piece. Recognizing subjects as fellow collaborators or as duet partners brings to the investigators moral vision a sense of commitment to a common task.

Chapter 5: Cultivating Moral Vision

In order to operationalize the metaphorical power of the body as music, investigators must develop their ability to improvise within the ethics of the face-to-face encounter. This ability requires investigators to balance their epistemic and moral obligations. An improvisational ethic of respect based in the face-to-face encounter can only be fully realized if investigators are trained to see body-subjects as intrinsically valuable. Through a carefully guided examination of aesthetic experiences, investigators may learn to cultivate and enhance this ability. Medical humanists and bioethicists must be willing and able to provide this training through the discerning use of works of art that provoke and stimulate moral growth through engagement and dialogue. In this chapter, I provide pedagogical suggestions for teaching clinical investigators how to develop their moral vision through exposure to the curriculum of the medical humanities.

In the first section of this chapter I will critically assess the current state of research ethics education. The current program of instruction in the responsible conduct of research (RCR), while helpful for avoiding violations of scientific integrity, is inadequate for properly forming future investigators' moral vision. Research ethics training should not merely be concerned with complying with the federal regulations regarding human research subject protections, though that aspect of training is certainly important. In addition, it should help investigators develop moral habits that broaden their understanding of the ethical issues that arise in the face-to-face encounter with human subjects. Showing respect for persons occurs on the level of the individual investigator-subject relationship. Developing, strengthening, and maintaining this relationship is

integral to both scientific integrity and the integrity of medical research as an ethical practice.

In the second section of this chapter, I will outline the learning objectives that I propose to satisfy through the pedagogical methods I describe in the third section. Moreover, I will describe how cultivating what I am calling *aesthetic attunement* to the body of the Other will result in the broadening of investigators' moral vision. Aesthetic attunement has both cognitive and existential components. As a purely cognitive capacity, aesthetic attunement could be described as a capacity for tolerating ambiguity without seeking certainty. In this sense, it resembles the idea of *negative capability* attributed to John Keats.[1] However, unlike the negatively capable person, an individual who has developed aesthetic attunement incorporates facts and reason within his explorations of ambiguity, paradoxes, and contradictions. Facts, especially concerning the production of an artwork and historical context of its emergence, are integral to aesthetic experience. Reason also has its place as part of the reflective intelligence cultivated by exposure to aesthetic experiences. As an underlying component of moral vision, aesthetic attunement demands that investigators be open to intimacy and introspection. Through training in an aesthetic theory of perception, investigators will learn to see their engagements with bodies, persons, and dialogue as opportunities for acknowledging and excavating their core beliefs about embodiment. This kind of inward turning can be catalyzed by an experience of the sacred, beautiful, tragic, transcendental, and sublime. However, in order to allow these experiences to percolate and gestate within the aesthetic mind, this mind must first be able to seek them out. Training the mental

[1] John Keats, *The Complete Poetical Works and Letters of John Keats* (Cambridge, MA: Houghton Mifflin, 1899), 277.

habits and moral sensitivity of the investigator is the first step towards developing moral vision. Investigators must learn to develop their capacity for self-reflection as well as demonstrate how showing reverence for the body of the Other and discernment about their access to subjects' bodies respects subjects as persons. These capacities may be developed by exposure to aesthetic experiences and instruction in how to develop the link between aesthetic attunement, moral vision, and investigators' moral obligation to respect persons.

In the third section of this chapter I will describe how training in the medical humanities will help course instructors in the curriculum I am proposing meet these learning objectives. In Ronald Carson's view, "literary skills are needed, the skills of close reading—a feel for pathos, a discriminating ear, a discerning eye, an analogical imagination, a way with words."[2] Although Carson refers to this set of skills as "literary skills," they may also be understood as partially constitutive of aesthetic attunement in general. They need to be supplemented, however, by a philosophical understanding of the subjective experience of embodiment that is grounded in phenomenology. Taken together, these skills are part of the requisite skills and attitudes that each instructor will need to bring to the curriculum in order for it to be a successful pedagogical tool. Each skill might be deployed differently in each context that I discuss below, but the general sense of attunement to dialogue and to the subjectivity of the Other remains a constant theme of the investigator-subject relationship. With these thoughts in mind, I begin this section by showing how visual images may be used as a starting point for developing moral vision. Although I have already used some of the techniques that will be developed

[2] Ronald A. Carson, "Teaching Ethics in the Context of the Medical Humanities" *Journal of Medical Ethics* 20, no.4 (December 1994): 238.

in this section in earlier parts of the dissertation, this section will provide an assessment of how these techniques have worked in the context of medical education. I will use examples from my own experience at the University of Texas Medical Branch to indicate how exposure to visual images challenges medical students' preconceived notions about body types, racial stereotypes, and gender roles. Learning to see and interpret visual images is an important part of pedagogical strategies aimed at cultivating aesthetic attunement. Bodies speak in images through gestures, poses, expressions, context, and other qualities chosen by the artist. By developing skills of deep looking through careful study of visual images generated by scientists and artists, investigators can learn to expand their moral vision. Learning to see the essential features of a painting, drawing, or other work of art is analogous to feeling for the essence of the person who has agreed to become a human research subject. I then move from the visual image to the images of clinician-investigators and their relationships with subjects as they appear in works of literature. Using Margaret Edson's *W;t*, I indicate how the use of allegorical and metaphorical images illuminates moral values of trust and respect in the subject-investigator relationship. Expanding on these themes as they are found in Edson's play, I move to a discussion of how a role-playing exercise modeled on the standardized-patient experience might help students develop the skills of improvisation outlined earlier in the dissertation.

In the final section of this chapter I will return to Nikita's story in order to map out how an ideal investigator would respond to some of the queries raised in the first chapter. Ideally, an investigator who has developed his sense of moral vision will be attuned to Nikita's subjective experience and will refrain from treating her as a mere

object. This attunement is a creative and improvisational mode of being that emanates from a commitment to respect subjects as persons. For some investigators, such a mode of being will come naturally. For others, careful attention to how they engage subjects will be required. Developing and maintaining daily habits of self-reflection and self-monitoring will be essential. Learning to reflect on one's own embodiment is essential to recognizing the subjectivity of the Other.

By broadening and deepening moral vision through aesthetic attunement, investigators can explore the nuances of human relationships and recognize how essential these relationships are to the development of their character as well as their professional identity. Furthermore, they will discover how strengthening their relationships with subjects will lead to better outcomes in terms of recruitment and retention. Exposing clinical investigators to aesthetic experiences offers an opportunity for cultivating relationships with subjects that are based on mutual respect and recognition.

RETHINKING RESEARCH ETHICS EDUCATION

Research ethics education is required of all institutions receiving NIH grants for human subjects research.[3] Instruction in the ethics of research using human subjects is often combined with RCR training, which tends to devote the majority of time to issues of publication ethics, data integrity, conflict of interest, and general research misconduct. To its credit, the NIH's mandate that investigators complete RCR training does require significant time to be spent in a face-to-face instructional context. Investigators are also required to demonstrate their knowledge of the norms of human subjects research. It is in these areas of instruction that the curriculum I describe below can be especially effective.

[3] National Institutes of Health, "Required Education in the Protection of Human Research Participants" Release Date: June 5, 2000 (Revised August 25, 2000) NOTICE: OD-00-039, (June 2000) http://grants.nih.gov/grants/guide/notice-files/not-od-00-039.html.

Furthermore, one of the suggested areas of competence as part of the RCR training is familiarity with "contemporary ethical issues in biomedical research."[4] This fairly vague description of the core content of RCR training leaves room for a curriculum that does not superficially address these issues but provides course materials that stimulate the moral imagination. One of the major drawbacks to fully integrating a cumulative and comprehensive curriculum within the current model is the relatively small amount of time that is required for investigators to spend in session. Currently, the NIH requires investigators to spend only eight hours every four years in RCR training, although it does encourage semester-long seminars. It is puzzling that the NIH would suggest but not require at least a semester-length seminar on RCR training. Of course, there are certainly some institutions that would struggle to provide such a curriculum and one might expect some resistance from some investigators to such a time commitment. However, if the NIH is serious about RCR education, investing in a semester-long course does not seem that burdensome. The NIH is also interested in spreading out the instructional hours over a wide swath of the average investigator's career. NIH currently requires that investigators commit to RCR training at least once during each stage of their career—that is, during the undergraduate, postbaccalaureate, predoctoral, postdoctoral, and faculty stages. Each stage offers a chance to develop skills of aesthetic attunement for those investigators who will be working with human subjects. Most importantly, such a curriculum may begin before students even reach the stage where they will be working with human subjects on a regular basis. While this program might initially meet with some resistance from students who will not have worked with human subjects yet, there is hope that training young investigators before they are socialized to think as some of the investigators mentioned above will prevent their moral vision from being corrupted.

[4] National Institutes of Health, "Update on the Requirement for Instruction in the Responsible Conduct of Research" (November 2009), http://grants.nih.gov/grants/guide/notice-files/NOT-OD-10-019.html.

Assessments of the goals and quality of RCR training point to a large variation across institutions in these areas.[5] A recent survey of students who had completed RCR training noted that most had gained an understanding of research ethics, but had not experienced a significant change in their skills of moral reasoning or in the attitudes towards moral problems.[6] Another survey taken by students prior to RCR training at the graduate or postdoctoral level found that even those who had taken an RCR course before beginning their current program failed to retain core knowledge of research norms.[7] For example, only 40 percent of the students surveyed could properly recall the principles of the Belmont Report. Yet, an even more recent study has shown that some institutions are exceeding the federal mandates for RCR instruction.[8]

Many of the research programs that have received federal funding for human subjects research use online modules as a way to meet the federal requirements for compliance in research ethics training. The general intent of the program in research ethics I outline below is to avoid the tendency to treat research ethics education as compliance training. Part of the reason for this aim is that online modules do not adequately capture the broader notion of respect for persons that I have outlined in this dissertation. Online modules like CITI and the NIH Office of Extramural Research's module base their training on the assumption that respect for persons begins and ends with respecting autonomy.[9] Although the latter does mention that informed consent is an

[5] Dena K. Plemmons, Suzanne A. Brody, and Michael W. Kalichman, "Student Perceptions of the Effectiveness of Education in the Responsible Conduct of Research," *Science and Engineering Ethics* 12, no. 3 (July 2006): 571-582 and Alison Antes, Xiaoqian Wang, Michael Mumford, Ryan Brown, Shane Connelly and Lynn Davenport, "Evaluating the Effects that Existing Instruction on Responsible Conduct of Research has on Ethical Decision Making," *Academic Medicine* 85, no.3 (March 2010): 519-526.

[6] Plemmons et al., 575.

[7] Elizabeth Heitman, Cara H. Olsen, Lida Anestidou, and Ruth Ellen Berger, "New Graduate Students' Baseline Knowledge of the Responsible Conduct of Research," *Academic Medicine* 82, no.9 (September 2007): 838-845.

[8] David Resnik and Gregg Dinse, "Do U.S. Research Institutions Meet or Exceed Federal Mandates for Instuction in Responsible Conduct of Research? A National Survey," *Academic Medicine* 87, no.9 (September 2012): 1237-1242.

[9] Collaborative Institutional Training Initiative (CITI), https://www.citiprogram.org/Default.asp? ;and National Institutes of Health, Office of Extramural Research, "Protecting Human Research Participants" http://phrp.nihtraining.com/respect/01_respect.php.

ongoing process, it does not uncover the moral obligations that underlie the investigator-subject relationship. Stretching out the notion of informed consent as a way to describe the entire context of the dialogical relationship between investigator and subject is inadequate. It simply asks the informed-consent process to do too much and discounts the value of the face-to-face encounter as the basis for the dialogical relationship.

As an alternative to these programs, I propose a stand-alone, comprehensive curriculum that focuses on the moral development of graduate students and postdoctoral fellows who have just entered the field. The intent of such a program would not be to help researchers quickly make practical decisions that involve moral components but to help them reflect on their on-going moral obligations. Instructors in the program would seek to aid their students in developing an overall disposition that places moral obligations within the context of respect for persons. Such a curriculum would function more as a tool of preventive ethics than as a problem-solving tool of quandary ethics. As such, I am not proposing another framework for applied ethics. Instead, I am offering an ethics of practice. The emphasis in research ethics should be on recognizing moral problems and avoiding moral blindness.[10] Moral vision is important as it reveals the contours of the ethical relationship by keeping the focus squarely on the subject. Understanding the rhetorical devices that support the cultivation of moral vision is the first step towards developing a coherent program in research ethics.

Aesthetic experience prepares the investigator for the face-to-face encounter. Although the totalizing power of the clinical gaze remains a constant presence that threatens to unjustly limit the infinity of the Other, training in aesthetic attunement softens the clinical gaze, making it broader and deeper, but also gentler. Through developing skills of self-reflection by reflecting on the gaze, the Look, and the face,

[10] Michael W. Kalichman and Dena K. Plemmons, "Reported Goals for Responsible Conduct of Research Courses" *Academic Medicine* 82, no.9 (September 2007): 846-852; and Brian Schrag, "Teaching Research Ethics: Can Web-Based Instruction Satisfy Appropriate Pedagogical Objectives?" *Science and Engineering Ethics* 11, no.3 (July 2005): 347-366.

investigators learn to uncover the unhomelikeness of the body. They also learn to decipher subjectivity as expressed by the face. Both are integral to the development of an improvisational ethic.

The improvisational ethic arises out of consideration of body-subjects through the various artistic forms mentioned above. The clinical gaze forms the epistemic baseline while the federal regulations form the normative. Yet, these baselines need not inhibit movement towards the Other. In fact, they are meant only to serve as the means for grounding the research enterprise. By viewing art that provokes and disturbs the hegemony of the clinical gaze, investigators learn to reevaluate their habitual responses to subjects' bodies. To truly respect persons, one must be able to deepen and broaden their commitments to the Other through an improvisational ethic of recognition and reciprocity.

THE AESTHETIC FOUNDATION OF MORAL VISION

My use of the term *aesthetics* in this dissertation is a combination of several meanings of the term. Since the eighteenth century, aesthetics has traditionally been understood as a branch of philosophy concerned with the rational construction and evaluation of judgments about art and beauty. However, as several commentators have indicated, there is a much older tradition of aesthetics as a theory of sense perception in general.[11] I propose a notion of aesthetics that emphasizes the skills and attitudes necessary to perceive, interpret, and respect the Other as a body-subject. Dwelling on questions of beauty, symmetry, and proportion for their own sake is of little moral value when what is at stake is training investigators to see the intrinsic value of persons as

[11] See Wim Dekkers, "The Lived Body as Aesthetic Object in Anthropological Medicine," *Medicine, Health Care and Philosophy* 2, no. 2 (May 1999):117-128; Alan Bleakley, Robert Marshall, Rainer Brömer, "Toward an Aesthetic Medicine: Developing a Core Medical Humanities Undergraduate Curriculum," *Journal of Medical Humanities* 27, no.4 (Winter 2006):197-213.; and Marcus Düwell, "Aesthetic Experience, Medical Practice, and Moral Judgment. Critical Remarks on Possibilities to Understand a Complex Relationship" *Medicine, Health Care and Philosophy* 2, no. 2 (May 1999): 161-168.

body-subjects. The kind of aesthetics that I have in mind is focused on cultivating receptivity, recognition, and reflection on the body of the Other in order to expand moral vision and identify the scope of moral responsibility. It is not about making value judgments about particular bodies, but moving from the scientific objectification of bodies towards respecting persons as body-subjects. If, as Levinas suggests, "ethics is an optics," then research ethics must be rooted in the cultivation of moral vision.[12] By incorporating some of the metaphors described above within the curriculum described below, investigators will learn to approach the Other as one would approach a work of art. Truly respecting persons necessitates giving them the respect one would an aesthetic experience, which is valued in itself. This capacity for respecting persons on a deeper level than simply recognizing their autonomy is cultivated by developing the capacity for aesthetic attunement.

Attunement to the body of the Other with an aesthetic gaze that illuminates the essence of humanity in each human subject is a skill that may be honed by instruction in the medical humanities, especially the fine arts. The painter and novelist James Templer has noted that "the images of art teach viewers how to visually organize and think about the images of the world that present themselves to their eyes."[13] For example, viewing paintings from postimpressionists like Paul Cézanne "forces a reassessment of how people see each other."[14] The skill of self-reflection and the ability to reassess how one sees the world and the Other are part of the overall goals of developing aesthetic attunement.

Reflection on how one perceives the world is an introspective process that reveals how previous experiences have shaped moral vision. In his phenomenology of perception, Merleau-Ponty makes the radical claim that the world appears as visible only

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[12] Levinas, 8.

[13] James Templer, "Medical-Technology Art: A Reunion of Art and Medicine" (PhD diss., University of Texas Medical Branch, 2002), 191.

[14] Templer, 40.

to shape human capacities for perception. In his view, "quality, light, color, depth, which are there before us, are there only because they awaken an echo in our body and because the body welcomes them."[15] Merleau-Ponty argues that art does not simply enhance perception but creates it. For example, artists like Henri Matisse teach how to see bodies "not in a 'physical-optical' way but rather as structural filaments, as the axes of a corporeal system of activity and passivity."[16] Though it is unclear which of Matisse's many compositions Merleau-Ponty had in mind when making this claim, he may have been referring to "La Danse" (Fig. 7). Perhaps one of Matisse's best known works, this large oil painting of five nude female figures holding hands and moving in a circle is a fine illustration of Merleau-Ponty's theory of the visible flesh of the world. What at first glance appears to be an unfinished and crude representation of women dancing turns out to be an ingenious use of soft edges and undefined lines to capture the rapidity and fluidity of their movements. The figures in the lower right hand corner are moving so quickly that their hands have slipped free of one another. The shapes of the land and sky are unrefined and lack any detail whatsoever, creating an image of a Platonic world of pure form and essence. As Merleau-Ponty points out, the dancers are connected by their corporeality yet maintain their own bodily schemas and rhythms. Investigators can develop their skills of attunement to these schemas and rhythms through guided instruction and exposure to works of art by masters like Matisse and Cézanne.

[15] Maurice Merleau-Ponty, *The Primacy of Perception: And Other Essays on Phenomenological Psychology, the Philosophy of Art, History, and Politics*, trans. William Cobb (Evanston, IL: Northwestern University Press, 1964), 164.

[16] Ibid., 184.

Figure 7: Henri Matisse, *Dance (1)* Paris 1909 Oil on canvas, 8' 6 1/2" x 12' 9 1/2", Metropolitan Museum of Art, New York, NY. © 2012 Succession H. Matisse / Artists Rights Society (ARS), New York. Used with permission.

A research ethics curriculum rich in aesthetic experiences and the methodology of the medical humanities blends the practical value of seeing with the ethical value of looking. Although it is a bit broad, Jerome Stolnitz's definition of the "aesthetic attitude as disinterested and sympathetic attention to and contemplation of any object of awareness whatever, for its own sake alone" draws attention to how such an attitude might inform moral contemplation of the body of the Other.[17] To find the intrinsic value of a subject, one must first be willing to adopt this kind of attitude. Although at first glance, the term *disinterested* seems a bit out of place, Stolnitz uses it to distinguish the aesthetic attitude from the everyday sense of looking at objects only in terms of their potential usefulness for one's own projects. In order to reform the clinical gaze, the instrumentality of human subjects must become secondary to the recognition of their intrinsic value. Forming a disinterested gaze at the beginning of the face-to-face encounter allows investigators to redirect their focus towards the person in front of them while still being mindful of the scientific purpose of the encounter. In this sense, investigators are asked to be objective without objectifying the body of the Other. Also

[17] Jerome Stolnitz, "The Aesthetic Attitude: From *Aesthetics and Philosophy of Art Criticism*" in *Aesthetics: A Critical Anthology*, eds. George Dickie, Richard Sclafani, and Ronald Robin (New York, NY: St. Martin's Press, 1989), 346.

important for Stolnitz is the notion of sympathy as an attribute of the aesthetic attitude. This too is a skill that may be developed through exposure to aesthetic experiences that represent aspects of the sacred, beautiful, tragic, hideous, or macabre. Each experience of these common aspects of human life is a small moral moment, an occasion for spiritual growth that will help investigators gaze sympathetically upon the body of the Other.

Once investigators have adopted a general aesthetic attitude, their skills of perception may be enhanced so that they are able to perceive the connections between aesthetic and moral vision. Following Husserl, exterior perception enables investigators to see that "surrounding a nucleus of real representation … there is an infinite halo of emptiness, of invisibility."[18] The face is the nucleus of representation; the Other is the halo of emptiness. Yet it is not invisibility that binds us to the flesh of the world, but visibility. This halo is filled with outer and inner horizons of perception.[19] The metaphors described in chapter 2 condition investigators to miss the inner and outer horizons. Perception of the face is colored by their perceptual interests, which "guid[e] the perceptual movements."[20] To perceive the Other one must first be interested in seeking them out. The desire to close these horizons and subsequently claim to have apprehended the Other in their totality is the negation of the Levinasian Desire for the Other. It is also a product of the persuasiveness of the mechanical, agricultural, and industrial metaphors. These metaphors delimit perception by shaping perceptual interests according to the clinical gaze. It is no wonder, then, that subjects and investigators perceive bodies differently and these perceptions create "different perceptual worlds."[21] Reshaping these perceptual interests is the first step towards respecting persons. Training in aesthetic attunement "regains [s] access to this primary, ethical vision" of the face.[22]

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[18] Christian Hick, "The Art of Perception: From the Life World to the Medical Gaze and Back Again" *Medicine, Health Care and Philosophy* 2, no.2 (May 1999): 130.

[19] Ibid., 131.

[20] Ibid., 132.

[21] Ibid., 133.

[22] Hick, 138.

Although comparing human subjects to aesthetic objects could potentially have some dangerous implications, in Marcus Düwell's view, "the human body, as an object of aesthetic experience, is not depersonalized but manifests a moment of its moral existence."[23] This moral moment is manifested as the "freedom of the other" in its particularity and contingency.[24] This freedom is the subjectivity of the Other expressed through the body and recognized by aesthetic attunement (not aesthetic judgment). Part of the experience of viewing a work of art is identifying features that express its particularity and contingency. The uniqueness of a piece such as Leonardo da Vinci's *Mona Lisa* or Sandro Botticelli's *Birth of Venus* is part of the aesthetic experience of viewing it. Other works specifically address the contingency of life, such as John Cage's *Music of Changes*, which was composed using the *I Ching* to randomly determine tone, pitch, and tempo. These features are also identifiable as part of the subjectivity of the Other. Making the connections between the face-to-face encounter and the development of an ethic of improvisation is much simpler when works of art are used to convey the metaphorical concepts that underlie the moral vision that unites ethics and aesthetics. These connections can then emerge as part of the meta-discursive analysis of embodiment brought about by group discussions of individual aesthetic experiences.

Aesthetic attunement is developed not simply through gazing at paintings, but also through changes in the rules of scientific and ethical discourse, which is in turn brought about by those persons who have been exposed to aesthetic experiences. In poet and physician John Little's view, "discourses frame our ethical understanding, our ethical language, and ultimately our ethical practices."[25] Little argues for the indirect ethical link between aesthetics and ethics through the enlargement of discourse. This expansion does

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[23] Marcus Düwell, "Aesthetic Experience, Medical Practice, and Moral Judgment. Critical Remarks on Possibilities to Understand a Complex Relationship," *Medicine, Health Care and Philosophy* 2, no. 2 (May 1999): 163.

[24] Ibid..

[25] John Miles Little, "Is there a Real Nexus Between Ethics and Aesthetics?" *Journal of Bioethical Inquiry* 7, no.1 (March 2010): 94.

not necessarily have to involve particular investigators having direct aesthetic experiences themselves, but may result from introduction to the discourse of aesthetics and ethics through other means. Exposure to the nightly news or an internet article that addresses ways of thinking about the body informs the moral vision of investigators by introducing them to the ever changing social imaginary. For example, Shepard Fairey's image of then-candidate Barack Obama has become an iconic image for millions of individuals.[26] In the mixed media stencil, then-Senator Obama is depicted in a manner that seems to show him gazing attentively at the viewer with a mixture of polite interest and idealistic reverie. His portrait is bathed in a blue and red color scheme, which symbolizes his campaign promise to unite both red states and blue states. Supporters and opponents of President Obama can clearly identify this image because of the way it has shaped the discourse surrounding Obama's rhetoric of hope and change. This image and those like it shape the subjectivity of the public, of which investigators are certainly members, by offering alternative subjectivities. As Little argues, media aesthetics are always already tuned to highlight the most polarized, if not always the most substantial, ethical issues. Little's suggestion regarding the discussion of media outside the world of fine art should be incorporated as part of the medical humanities curriculum proposed in this chapter. Aesthetic experience need not be limited to museums, theaters, auditoriums, and galleries.

Through the media, museums, and other dispensaries of aesthetic experiences the "aesthetic-ethical issues of our time become the material for our secular spirituality."[27] Pedagogical value may be derived from conversations about images of the body that are not derived directly from medical contexts. For example, the Falling Man, a photo taken during the events of September 11, 2001, has elicited a strong emotional response from

[26] Shepard Fairey, "PROGRESS" http://www.obeygiant.com/headlines/Obama.
[27] Little, 99.

the public.[28] Indeed, it is likely to evoke a strong response from anyone who gazes upon it. The questions that come immediately to the fore when considering such an image are both ethical and aesthetic. What is happening in this image? Should I be viewing this? Is it right to gaze upon this body, in this context? Is this image exploitative? Does it harm the person who is depicted in the image? Moving from the aesthetic to the ethical creates a space for reflection on the nature of embodiment. Images such as these confront us, shaping our intuition and moral vision.[29] Discussion of how the brain processes these images and makes both ethical and aesthetic judgments should also be part of the conceptual process of curricular development.

NEUROAESTHETICS AND NEUROETHICS

One of the central questions when framing a novel way of approaching a set of ethical problems is whether the ethical framework being considered can be practically applied. In this case, there is some debate over how carefully guided aesthetic experiences translate into changes in moral vision. At the root of this debate is a concern about how one would provide empirical evidence for the connection between a particular ethical intervention and a change in behavior or moral reasoning. Instead of delving into this territory directly, I will approach the question from the other side of the spectrum. Although neuroaesthetics and neuroethics are fairly new fields, there is some evidence from various scientific studies that suggests a link between areas of the brain that process aesthetic experiences and those that make moral judgments. If the processing of aesthetic and moral stimuli is already conjoined in the brain, then it seems reasonable to suggest that education that refines one area of perception will enhance the other.

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[28] Richard Drew, "The Falling Man" (September 2001), Photograph. Reprinted in Tom Junod, "The Falling Man" *Esquire* (September 2003). http://www.esquire.com/featurens/ESQ0903-SEP_FALLINGMAN.

[29] Little, 99.

According to a review article by Dahlia W. Zaidel and Marcos Nadal, "neural networks in the human brain that are intimately linked with the limbic system might encode ethical and aesthetic principles."[30] Furthermore, various researchers cited in this review article have noted that there is significant overlap in areas that deal with the cognitive and affective processing of moral and aesthetic judgments.[31] Moral psychology conceived in terms of the biological prerequisites for moral reasoning is believed to be an inherited characteristic that develops in the "orbitofrontal and insular cortices."[32] Beyond these general findings, there are some areas of neuroethics and neuroaesthetics that have implications for how persons and objects are processed by the brain.

Neuroscientists have discovered that there are certain areas of the ventral temporal cortex that are used specifically to process and recognize faces.[33] Posner P. Mitchell, Todd F. Heatherton, and C. Neil Macrae discovered that semantic judgments about persons are processed in a different area of the brain from the sites used to process semantic judgments about objects. When comparing words that describe people with words that describe objects, the parts of the brain involved in "self-monitoring, retrieval of personally relevant memories, and the perception of socially relevant stimuli such as eye gaze, biological motion, body parts, and faces" are used.[34] Processing information about the face of the Other is clearly a complex process that involves areas of the brain also used in moral deliberation. Investigators also discovered that the brains of some subjects in a resting state seem to be occupied with "social-cognitive processes such as the simulation of other minds, the flexible use of social and moral knowledge, self-

[30] Dahlia W. Zaidel and Marcos Nadal, "Brain Intersections of Aesthetics and Morals," *Perspectives in Biology and Medicine* 54, no. 3 (Summer 2011): 369.

[31] Ibid., 374-75.

[32] Ibid., 369.

[33] Laura Helmuth, "Where the Brain Tells a Face from a Place," *Science* 292, no. 5515 (April 2001): 197.

[34] Posner P. Mitchell, Todd F. Heatherton, and C. Neil Macrae, "Distinct Neural Systems Subserve Person and Object Knowledge," *Proceedings of the National Academy of Sciences* 99, no. 23 (November 12, 2002) : 15240.

referent memory, emotion regulation, and the perception of socially relevant stimuli."[35] These findings might suggest neural analogues for the Levinasian Desire for the Other mentioned in a previous chapter. At the very least, they suggest that the brain processes objects and human faces separately, a claim that would seem to challenge the notion that persons are literally seen as objects. It is unclear how the semantic judgments made about persons and objects affect how each is treated. However, there is some neurological evidence to suggest that mirror neurons are used to process aesthetic experiences. These same neural pathways have been linked to the development of empathy.

Although investigators have yet to empirically confirm the presence of mirror neurons, there is enough evidence to posit the existence of a system of neural correlates of empathy. Neuroscientists refer to this system as the human mirror network system (hMNS).[36] A study by E. Greimel, et al. showed that the hMNS develops over time as a function of experience, including exposure to sensory and cognitive experiences like judging the emotional valence of faces.[37] Another study, by M. Iacoboni and colleagues, demonstrated that the hMNS uses contextual clues to determine the intentions of others.[38] These and other studies seem to suggest that there may be a neural pathway to intersubjectivity through interpreting the emotions of the self and others as an expression of empathy. Interpreting the actions of the Other is an expression of intercorporeality as well as bodily intentionality. Furthermore, there seems to be a correlation between activity in the hMNS and motor behavior related to the aesthetic experience of music.[39] The evidence from neuroaesthetics and neuroethics seems to at least provisionally

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[35] Mitchell, 15241.

[36] E. Greimel et al., "Development of Neural Correlates of Empathy from Childhood to Early Adulthood: and fMRI Study in Boys and Adult Men," *Journal of Neural Transmission* 117, no.6 (April 2010): 781-791.

[37] Ibid., 788.

[38] M. Iacoboni, et al., "Grasping the Intentions of Others with One's Own Mirror Neuron System," *PLOS Biology* 3, no.3 (March 2005): 529-534.

[39] S. Nieminen et al., "The Development of Aesthetic Responses to Music and Their Underlying Neural and Psychological Mechanisms," *Cortex* 47, no.9 (May 2011): 1138-1146.

support the idea that the capacity for aesthetic experience may be innate. More importantly, it may be correlated to empathy through the linking of "genetically determined third order mirror networks that may encode ethical principles and aesthetics."[40] While I am certainly not claiming any expertise in any of these areas, the evidence gathered by the investigators cited seems to suggest a neural correlation among aesthetic judgments about the face, empathy, and moral judgments.

Another possible empirical basis for the notion that aesthetic training can help investigators cultivate moral vision is the concept of neural plasticity. In the neuroscientific literature, *neural plasticity* describes the brain's capacity to "restructure itself in response to experience."[41] Although neural plasticity seems to decrease as one ages, there is still a sense that the theory of plasticity might support a neural capacity for replacing a morally deficient metaphorical understanding of the body with one that recognizes the intrinsic value of body-subjects. Furthermore, it is not really the eye that sees, but the brain. Drawing from the work of neuroaesthetician Semir Zeki, art historian John Onians explains that the visual cortex is structured as an eye. It is these parts of the brain that "see." Vision is not simply a matter of the eye projecting images through the optic nerve for the brain to decode.[42] These parts, known as V1-V5, work together to interpret images in terms of their color, motion, and presence or absence of faces or objects. Thus, a curriculum designed to cultivate moral vision should integrate the training of the faculties of perception as there may be a link between how the brain processes visual images and how it makes moral judgments about them.

Given the evidence provided above supporting the view that there may be a neurological connection between aesthetics and ethics, it remains to be seen how these

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[40] Luigi Agnati at al., "Does the Human Brain Have Unique Genetically Determined Networks Coding Logical and Ethical Principles and Aesthetics? From Plato to Novel Mirror Networks," *Brain Research Reviews* 55, no.1 (August 2007): 74.

[41] John Onians, *Neuroarthistory from Aristotle and Pliny to Baxandall and Zeki* (New Haven, CT: Yale University Press, 2007), 6.

[42] Ibid., 193.

connections might be reinforced through a medical humanities curriculum. The overall purpose of such a curriculum would be to show how the extrinsic value of art may be used to train investigators to look for the intrinsic value of persons. Instructors would model aesthetic sensitivity as a means for developing moral vision. By reflecting upon the sensory experience of viewing art, participating in a play, or reading a literary text, students would learn to see the body of the Other as more than a mere object. Furthermore, by using some of the metaphors described above as guides, students will be able to compare and contrast these experiences against a range of background assumptions about the nature of embodiment.

LEARNING TO SEE THE OTHER THROUGH EDUCATION IN A MEDICAL HUMANITIES CURRICULUM

Upon completion of the curricular activities described in this chapter, students should be able to successfully navigate a simulation of a research-ethics scenario that calls upon them to demonstrate skills of self-reflection, improvisation, and tolerance of ambiguity. A satisfactory navigation of this simulation will demonstrate that students have mastered four learning objectives. First, students must be able to recognize all of the ethical issues involved in a particular case as well as discern their moral obligations to the subject. Second, they must be able to demonstrate how they would balance their scientific goals and their moral obligations in a real-world scenario. Third, students must be able to identify, describe, and apply the skills of aesthetic attunement to ethical problems inherent in the investigator-subject relationship. Fourth, students will have mastered their ability to synthesize various social, aesthetic, literary, and scientific discourses and critiques relevant to the nature and experience of human research subjects. These learning objectives go beyond the mere recitation of the norms of human subjects research, as required by RCR training assessments, to demand that students demonstrate their ability to recognize the intrinsic value of the human research subject as a person worthy of

respect. Assessment of the degree to which students have satisfied these learning objectives will be based on a series of reflective writing assignments, a comprehensive examination, and the above-mentioned role-playing scenario.[43] In the next section I will describe how a medical humanities curriculum would satisfy these learning objectives.

Before outlining the details of how a medical humanities curriculum would cultivate moral vision, I will briefly explain what such a curriculum can and cannot be expected to do. Some commentators have argued that the kind of curriculum proposed below provides a "'simulation' of the wider experience of life necessary for mature interaction with other human beings" not otherwise available.[44] Instruction in the medical humanities does not provide a simulation of experience. Instead, it provides a space for reflection on different kinds of experiences. Art, music, and literature are not mere simulations of reality. Aesthetic experiences train the viewer in how to see beneath the surface, to explore the essence of the real as it is presented in appearances. Mark Perry et al. suggest that some aesthetic experiences are "observational," which are to be distinguished from "experiential" pedagogical methods. While in the context of the article this choice may be merely a practical way of dividing the territory between the hands-on making of art and engagement with works of art, such a distinction only serves to indicate the value of active engagement over passive observing. Yet, as David Perkins suggests, the eye is never passive. To observe in his sense of the term is already to engage and participate in making meaning out of an aesthetic experience. Although some arts programs have been shown to improve observational skills as tested in a clinical environment, the goal of instruction in a medical humanities curriculum is not the enhancement of the clinical gaze but its reformation.[45]

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[43] Antes et al., 525. Antes et al. suggest that current RCR training may be harmful and one way to correct it is through "realistic performance" as part of the assessment of RCR knowledge transfer.

[44] Mark Perry et al., "The Effectiveness of Arts-Based Interventions in Medical Education: A Literature Review" *Medical Education* 45, no.2 (February 2011): 142.

[45] Johanna Shapiro, Lloyd Rucker, and Jill Beck, "Training the Clinical Eye and Mind: Using the Arts to Develop Medical Students' Observational and Pattern Recognition Skills," *Medical Education* 40,

As physician and medical humanist Rolf Ahlzén characterizes it, the compensatory model of medical humanities in the context of medical education is rhetorically positioned as "some sort of counterbalancing force to … scientific training, compensating for risks inherent in the medical gaze."[46] This model places medical humanities as both the disciplinarian of and the handmaiden to medical science. In the context of research-ethics education such a model would be seen as a soft discipline overlaying the hard core of clinical science. The compensatory model of medical humanities may serve to discipline the clinical gaze, but it will not be able to reform it. Instead, what is needed is a model of cultivating moral vision that is already embedded within the clinical science community. Such a model would be part of the educational process itself, not be forced to insert itself into the clinical space to be seen as simply another checklist to fill or as a pleasant but useless distraction from the "real" work of science.

As an alternative, Ahlzén proposes an integrated model that focuses on embodiment, which is at the root of both medical science and medical humanities. Part of the means for achieving the goals of medicine involves "*conceptual, ethical and historical scrutiny* in order to place the practice of medicine in a larger socio-historical context and rightly evaluating [it] as such."[47] These forms of critique are subsumed under an aesthetic appreciation of how these forms are expressed in both visual and foundational images of the body. In other words, viewing images of the body with aesthetic attunement necessarily involves these forms of critique. It should be noted that Ahlzén's aesthetics is a little different from the one proposed above. He is more

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no.3 (March 2006): 263-268; and Jacqueline C. Dolev, Linda Krohner Friedlaender, and Irwin M. Braverman, "Use of Fine Art to Enhance Visual Diagnostic Skills," *JAMA* 286, no. 9 (September 2001):1020.

[46] Rolf Ahlzén, "Medical Humanities—Arts and Humanistic Science," *Medicine, Health Care and Philosophy* 10, no.4 (December 2007): 386.

[47] Ahlzén, 389. See also Paul Ulhas Macneil, "The Arts and Medicine: a Challenging Relationship," *Medical Humanities* 37, no.2 (December 1, 2011): 85-90. Macneil argues for a more critical and integrated model of the medical humanities.

interested in the emotional value of aesthetic experience and the role that emotions play in developing moral vision. However, one cannot simply reduce moral sensibility to various emotional states. Sensibility thrives at the level of raw experience. It arises prior to reflection on the affective or cognitive content of that experience and therefore must be integrated into the moral vision so as to be ready to hand at the appropriate moment. Ahlzén argues that emotions dominate the prereflective phase of aesthetic appreciation, while "intellectual analysis" prevails in the reflective phase.[48] While I am sympathetic to this view, it is only through training that these phases may be analyzed and considered in the context of the investigator-subject relationship. Aesthetic attunement as the groundwork for an improvisational ethic involves a mode of engagement that Ahlzén describes as "a process of amalgamation, where imaginative participation, involving emotional and aesthetic aspects, intimately interacts with distanced analysis, involving applying abstract concepts and logical deliberation."[49] Aesthetic attunement enables the practitioner to recognize the intertwining of the affective, conceptual, and ethical and to proceed to act according to how each reveals the intrinsic value of the Other.

As part of designing a medical humanities curriculum that follows the integrated model, Bleakley et al. refer to the cultivation of moral "sensibility (medical aesthetics) … [which] precedes sensitivity (medical ethics), where gathering evidence forms the basis for clinical and ethical judgment and appreciation precedes explanation."[50] This intertwining of sensibility and sensitivity results in an epistemic vision that is cultivated from a broader moral vision. Instead of grafting a moral vision onto an epistemic vision or pruning away morally deficient aspects of the moral vision of investigators, Bleakley

[48] Ahlzén, 390.
[49] Ahlzén, 389.
[50] Bleakley et al., 199.

et al. suggest using the medical humanities to "create the conditions of possibility" for learning clinical science as an aesthetically grounded practice.[51]

SHAPING MORAL VISION THROUGH ART CRITICISM

To seek out a methodology that can help investigators recognize ethical issues and provoke self-reflection on how they comport themselves towards human subjects is to seek a vision of medical research that is grounded in the medical humanities. Finding not only aesthetic value, but also a source of moral inquiry and reflection in a visual image is a task that requires careful training. According to the developmental model of aesthetic judgment, exposure to art within a specified curriculum leads to a "gradual decline of egocentrism, and at the same time, there is an increase in self-reflective activity with regard to aesthetic judgments."[52] Art historian David Perkins's *The Intelligent Eye* provides an excellent basis for a curriculum that cultivates moral vision through the viewing of visual images. In his book, Perkins seeks to develop what he calls "reflective intelligence" and "experiential intelligence."[53] From the attentive contemplation of art, students are able to build a network of experiences to draw from as they learn to use strategies for self-reflection and attunement. By developing "thinking dispositions," viewers of art are able to catch hidden meanings that a merely superficial glance does not reveal.[54] Perkins aims to aid his readers in developing these dispositions as a necessary corrective for what he calls "intelligence traps."[55] Incorporating Perkins's methodology into the traditional process of art criticism, which calls for viewers to describe, analyze, interpret, and respond, produces a rudimentary framework for cultivating aesthetic

[51] Ibid., 200. Actually, the article focuses on using this approach in medical school training programs, but its applicability to training clinical investigators is clear.

[52] Carol A. Mockros, "The Development of Aesthetic Experience and Judgment," *Poetics* 21, no.5 (May 1993): 413.

[53] David N. Perkins, *The Intelligent Eye: Learning to Think by Looking at Art* (Los Angeles, CA: Getty Publications, 1994).

[54] Ibid., 4.

[55] Ibid., 83.

attunement. The rudimentary nature of this process belies its usefulness for systematic study of any visual image. Investigators will likely feel comfortable with a process that proceeds along a predetermined path, yet will be able to deviate from this path in order to develop their individual aesthetic prowess.

Consider the image above (Fig. 8). At first glance it appears to be a photograph of a doctor and a patient in a hospital setting. The figure facing outwards is clearly a professional of some kind. He has a lab coat and a clipboard. It looks like the figure with his back turned has recently been injured. It appears that his back is covered in gauze and adhesive tape. Were I to leave the analysis there, Perkins would claim that I have fallen into one of the intelligence gaps. I have not given myself enough time to look and have been guilty of generating a hazy analysis. If I were to look again, I would try to determine the significance of the shapes in the background above the doors. This would lead me to complete a more thorough inventory of the photograph and reveal a series of bars connecting the ceiling to the doorway. I might also notice that some of the figures in the background are wearing uniforms that look like police uniforms. I would likely change my earlier assumption that these men are in a hospital and posit that they are in a jail or prison. At this stage, I would move to an analysis of the image.

To analyze a visual image is to seek that image's organizational logic. The photograph is clearly taken from a perspective that obscures a small portion of the hallway on either side. The space in the foreground and in the midground is quite busy; there are few indications that the photographer has any particular focus in mind. The eye is left to wander from the foreground to the midground on its own. The background is too dark, too heavily saturated to make out any details beyond the figures clustered together

on the right. From the composition of the piece, it looks to be taken by an amateur. Perhaps its lack of strong compositional features is an indication of the deterioration of the image, but it is difficult to decipher the "logic of figuration."[56] However, there is significant expressive content to discover. By assessing the affective impact of the composition, figures, and the action, I would surmise that the standing figures are sources of authority in the scene. Although the lighting in the reproduction is distorted, the shadow of the figure on the right adds a menacing touch to the overall impression of him. The patient's head is bowed, his shoulders are slumped. He is sitting on a table, not a chair, which may explain why he looks uncomfortable. If he is a patient, why is he being examined in the hallway? Why is the police officer's attention drawn away from the prisoner? Why is the doctor standing over his patient instead of sitting across from him in the chair in the left-hand corner? These are questions of interpretation that may be engaged as part of the third stage of criticism.

Seeking meaning is fundamental to the appreciation of art, especially when one is confronted with unfamiliar images. Discourse analysis offers a means for uncovering the discursive strategies at work in the production of images. Such an analysis involves seeking out the metaphorical and metonymic content of an image, looking for what is invisible or redacted and using historical information to deduce why that content has been hidden. Seeing visual images as rhetorical devices necessarily involves determining the conventions, rules, and central axioms that ground the discursive strategies referenced by the work. In Roland Barthes's view, "the code of the connoted system [of significations] is very likely constituted either by a universal symbolic order or by a period rhetoric."[57] In the photograph described above, I was able to decode the setting and the figures by

[56] Gillian Rose, *Visual Methodologies: An Introduction to the Interpretation of Visual Materials* (Thousand Oaks, CA; Sage Publications, 2007), 47. The phrase "logic of figuration" refers to the intended position of the viewer relative to the focal points of the image.

[57] Roland Barthes, *Image, Music, Text*, trans. Stephen Heath (New York, NY: Hill and Wang, 1977) , 18.

referring to the code of significations that indicates an institutional setting, in this case a prison. Furthermore, the clothing worn by each figure indicated their social status, occupation, and the reason for including them in the image. Placing the doctor, which history identifies as Dr. Solomon McBride, a colleague of Albert Kligman at Holmesburg prison, in the foreground indicates his disciplinary power over the body of the prisoner. However, the figures lurking in the background actually have more power over the prisoner's body than does Dr. McBride. He is, so to speak, in their house. Yet, both are united in a common rhetoric of docility and productivity, symbolized by the positioning of the prisoner with his back covered in allergenic materials and facing away from the viewer. Photographs, even those that seem straightforward like the one above, are paradoxical in that they have both denotative and connotative meaning. In order to interpret the connotative meaning, one must be able to integrate the descriptive, historical, and normative aspects of visual rhetoric. A rhetorical appraisal would be incomplete without considering the intended audience, the credibility of the rhetor, and the content of the message. Gillian Rose points to how images are always mediated by social context and "have their own agency."[58] Scientific images, like all images, are "multimodal."[59] Tracing out their relationship to the production of knowledge about the body involves mapping out images along various lines of inquiry.

The final stage of art criticism is to respond to the image based on the conclusions and observations made in the other stages as well as one's own preferences and personal feelings. In the previous paragraph I began the work of tracing out the symbolic meaning of the photograph. Placed in the context of this dissertation, the image has personal meaning in that it serves as a reminder of the corrupt moral vision of the physicians at Holmesburg without actually containing an image of the notorious Dr. Kligman. The prisoner in the foreground is a sympathetic figure, as I am familiar with the stories of

[58] Rose, 11.
[59] Ibid.

those who have been placed in similar circumstances. There are also subtle messages about racism and collaboration expressed through the images of Dr. McBride, the anonymous corrections officer, and the anonymous prisoner.

In order to prevent students from falling into the intelligence traps mentioned above, especially those that have an impact on moral vision, curricular activities that encourage them to deepen and broaden their looking must be outlined.[60] One such example of an intelligence trap is the tendency to make one's looking unfocused and to draw unsupported conclusions. Although one would expect investigators to be systematic in their thinking, there is a general tendency to fail to take stock of all the evidence provided by an image before responding to it. The failure to weigh alternatives seriously and thoroughly when attending to an aesthetic experience may indicate future difficulty in moral reasoning, especially when it comes to responding to the call of the Other. Reflective writing activities help students to slow down their looking. Upon first encountering an aesthetic object, students should be encouraged to make quick observations, then look again. Looking away when nothing new appears and looking back with a fresh eye also help to uncover hidden meanings. As an instructor, one should allow for the process to take place organically, with occasional probing questions like, "What is happening here?" and "Would someone please tell his/her story of what is going on in this image?"

Some of these techniques have been tested as part of the Humanities, Ethics, and Professionalism course at the University of Texas Medical Branch. During one session of the seminar, second-year medical students are asked to describe, analyze, interpret, and respond to a variety of images. Some are taken within the medical context while others are part of the art world. From my own experience, I have observed that most medical students are quite uncomfortable with the exercise. Some find the content disturbing,

[60] Perkins, 54.

while for others the open-ended format of the session challenges the patterns of rote memorization to which they have become acculturated. Those students who were perturbed by the indeterminacy and polysemic nature of the images kept asking for the "real story." Almost all students began the exercise by trying to diagnose the images. It did not seem to occur to them to simply describe what they saw using their own eyes, not the eyes of someone aspiring to be a doctor. Putting the accustomed ways of seeing the world, in this case the clinical gaze, into question is the essence of art that provokes moral inquiry.

Instructors in the medical humanities should choose works of art that capture the "madness of seeing" in the sense that they question how the "gaze institutes being and …. at the same time there is in the gaze a loss or perdition of the self."[61] The clinical gaze itself embodies this madness. It demands that investigators repress their own subjectivity so that they may gaze impartially at the body of the Other. Metaphorical representations of the body as factory or agricultural commodity form an insidious rhetorical program of socialization that teaches investigators to deny a crucial part of their own humanity, all without their realization. Training in aesthetic attunement allows investigators to reclaim a space for self-reflection while still completing their scientific tasks. To pull oneself away from the clinical gaze demands a stimulus that disturbs one's grasp of embodiment. Art that is of pedagogical value must disturb without completely alienating viewers. They may be repulsed and scandalized at first glance, but good art is able to bring their gaze back for a closer look. To be confronted by art is to find oneself trapped in a "moral snare causing perplexity and ethical confusion."[62] Art can cause investigators to "step back to the stratum of pre-conceptual open perception [from which] it is much easier to establish a web of shared reality."[63] Provocative art at its finest can shake one's aesthetics to the

[61] Christine Bucci-Glucksmann, "The Triumph of the Folds," in *ORLAN: A Hybrid Body of Artworks*, eds. Simon Donger, Simon Shepherd, ORLAN (New York, NY: Routledge, 2010), 1.

[62] Macneil, 87.

[63] Hick, 137.

core. Perception, after all, is socially constructed. This project of disruption of the taken-for-granted perceptual conventions is at the heart of many movements in art, especially the Surrealists and Dadaists.

Nonetheless, for the project of developing aesthetic attunement it is not sufficient for an aesthetic experience simply to provoke for the sake of it; there must also be some moral inquiry that it indicates. Art that inspires self-reflection creates "atmosphere[s] of heightened affect synergistic with the building of dispositions."[64] These dispositions are not merely thinking dispositions, but ways of seeing the world that translate into moral action. They are affective as well as cognitive, existential as well as pragmatic. Time spent reflecting on why a work of art is provocative, what it has provoked inside the self, and how this will change the way one sees the world is time spent finding "the means given me for being absent from myself, for being present at the fission of Being from the inside—the fission at whose termination, and not before, I come back to myself."[65] Self-reflection necessarily is an introspective as well as an extroverted experience. To paraphrase William Blake, cleansing the doors of perception reveals the self and the moment of perception as it really is, infinite.

French performance artist ORLAN's work is one example of a portfolio of art that seeks to provoke a variety of responses by expressing challenging interpretations of the "metamorphosis of the body, the self, the face."[66] In one of her earliest art actions, ORLAN devises a unit of measurement known as the ORLAN-body. In order to measure a space using the ORLAN-body, she lies down and draws a chalk line above her head. She then crawls to the next space, places another mark, then stands up to give a vertical measurement. She repeated this process in several different cities. In each action, which she called "MesuRages," she had two witnesses take pictures of her lying on the floor or

[64] Perkins, 5.
[65] Merleau-Ponty, *The Primacy of Perception*, 186.
[66] Bucci-Glucksmann, 1.

on the ground. ORLAN's intention as she put it at the time was to make an "attempt at putting in perspective the 'scale' of our institutions."[67] By placing her body among the numerous forms of objective measuring devices, ORLAN invites a critique of how public and private spaces express presence and absence. Her methodology confronts the boundaries between the objective and the subjective, as does the symbolism of the act itself. Moreover, she challenges the dichotomy of the soft human flesh of subjectivity and the cold density of objective measurement. One might imagine the result were she to inhabit a hospital or a clinical ward. How would the fleshly body measure the clinical space? Would such a body be absorbed into the instrumentality of the clinical gaze? In the third stage of her art action, ORLAN provides a clue to how these queries might be addressed. She washes the clothes she is wearing using whatever water is available, then extracts some samples of the dirty water and places them in labeled test tubes. The entire art action seems to be both a mockery of objectivity and a submission to the idolization of the public space. In fact, her works of Carnal Art push this dichotomy even further.

ORLAN describes Carnal Art as an aesthetic stance that "transforms flesh into language and reverses the Christian principle of the word turned flesh into the flesh turned word."[68] During her Carnal Art performances, ORLAN undergoes a series of cosmetic surgeries with only local anesthetic. She is awake and aware the entire time, even though most of the operations involve facial implants and rhinoplasty.[69] She is not only awake, but also recites postmodern monologues while surgeons slice through her epidermis. She manifests the speaking subject that retains its subjectivity even as it endures objectification. In her case, she does not simply endure objectification but chooses it and in so doing "disrupts the gaze and highlights the inscription of social

[67] ORLAN, "Mesurages (Since 1967)," in *ORLAN: A Hybrid Body of Artworks*, eds. Simon Donger, Simon Shepherd, ORLAN (New York, NY: Routledge, 2010), 18.

[68] ORLAN, "Carnal Art Manifesto (1989)," in *ORLAN: A Hybrid Body of Artworks*, eds. Simon Donger, Simon Shepherd, ORLAN (New York, NY: Routledge, 2010), 29.

[69] ORLAN's surgical performances: http://www.orlan.net/works/performance/

power on the body."[70] In one of her Carnal Art pieces, "The Reincarnation of Saint ORLAN/Images-New-Images: Fourth Surgery-Performance, Successful Operation," her surgeons wear costumes that seem to have been discarded from old French music videos. The operating room is turned into an artist's studio with pseudoreligious iconography, relics, and common objects like fruits and vegetables juxtaposed with surgeon's tools, blood, and gloved hands.[71] In these performance pieces she "navigat[es] between having a body and being a body."[72] Her work is ironic; she imitates that which she challenges so as to provoke a response from her audience. In another series of performances, she chooses to offer herself as a living composite of the classic beauty depicted by Botticelli, da Vinci, and other Renaissance artists. The reliquaries that capture her flesh and blood discarded from these operations stand as monuments to her ephemerality and satirize the practice of revering the flesh, while at the same time representing precisely that practice. ORLAN's work challenges the idea that the body is sacred, that it should not be commodified or objectified. Her choice of objectification exposes the paradox of embodiment, revealing as it does how the "sudden view of things from their reverse, usually unnoticed, side, comes upon us as a revelation, and such revelations are precisely those of Art."[73]

READING AND PERFORMING MORAL VISION

While almost all aesthetic experiences are able to help investigators cultivate moral vision, literature and the dramatic arts are especially effective at cultivating tolerance for ambiguity and arousing moral sympathy. Engagement in dramatic arts in particular can help investigators practice those skills that they will need to bring to the

[70] Gianna Bouchard, "Incisive Acts," in *ORLAN: A Hybrid Body of Artworks*, eds. Simon Donger, Simon Shepherd, ORLAN (New York, NY: Routledge, 2010), 72.

[71] ORLAN, "Carnal Art Manifesto," 41.

[72] Ibid.

[73] Edward Bullough, "'Psychical Distance' as a Factor in Art and as an Aesthetic Principle," in *Aesthetics: A Critical Anthology* ,eds. George Dickie, Richard Sclafani, and Ronald Robin (New York, NY: St. Martin's Press, 1989), 321.

face-to-face encounter. Since the aim of this curriculum is to develop aesthetic attunement to the Other, instructors would be remiss if they did not move beyond the text and the image to an interactive learning environment that compels students to physically encounter one another. Philosopher Martha C. Nussbaum offers an account of how literature can develop the skills of close reading mentioned earlier by Carson, especially as they concern the development of moral perception.

According to Martha Nussbaum, literature offers insight into the way that individuals consider the question of the good life, make choices based on emotion, reason, and understanding, and attempt to live with these choices.[74] Literature extends readers' life experiences, placing them in a position that is "both like and unlike the position we occupy in life."[75] Pedagogically valuable literature is identifiable by how the reader struggles to interpret the ambiguity of the text without abandoning it as incomprehensible. There is a fine line between incoherence and ambiguity, especially when it comes to the moral universe that readers generate from texts. Through close attention to the text, readers develop the capacity for generating their own interpretation of the moral universe each character inhabits. They may choose to place themselves either in or outside of that shared moral universe. Nussbaum assumes that literature is capable of creating similar bonds between characters and the reader as exist between the reader and other persons. This is not to say that readers simply simulate a moral universe. Instead, they allow themselves to inhabit it, to test the bonds between characters and themselves. This aesthetic experience allows for "genuine acknowledgment of the otherness of the other" in a way impossible in normal life.[76] Mutually exclusive moral scenarios may be sketched out in terms of their possible consequences in a way that is impossible to do when practical demands require that choices be made in a split second.

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[74] Martha C. Nussbaum, *Love's Knowledge: Essays on Philosophy and Literature* (New York, NY: Oxford University Press, 1990), 36.

[75] Ibid., 48.

[76] Ibid.

Nussbaum follows Aristotle closely in her ethical analysis, seeking to draw parallels between the habits that close readers of narratives adopt and the development of the moral self. For her, discernment is an integral aspect of *phronesis* or "practical wisdom." Readers develop this ability through close attention to the particulars of a narrative. In her view there is a link between *ingenium*, *phantasia*, and *aisthekai* through what she calls *perception*. *Phantasia* is the capacity for fantasy as a way of visualizing the particulars of a story, using memory to establish footings with the characters, and selecting morally salient facts.[77] Perception in this sense is the capacity for "seeing a complex, concrete reality in a highly lucid and richly responsive way."[78] Part of what makes a moral universe complex is the ambiguity within which moral agents operate.

In order to be truly successful at the goal of cultivating moral vision, investigators should allow themselves time to consider multiple interpretations of the structure, nature, and experience of embodiment. Allowing these to arise and converge will improve their relationships with subjects and by extension the quality of the data they are able to gather. The polysemic nature of literature and the face-to-face encounter pose "a question of meaning and this question always comes through as a dysfunction."[79] Scientific metaphors of the body deal with polysemy by appealing to physiology and biology as foundational images. These map the space of the body-subject by delimiting which interpretations of the body will be seen as scientifically valid from those that may draw attention away from the scientific credibility of the research protocol or invite questions about its cultural, political, or ethical significance. Yet, part of the social function of medical research requires navigating ethical gray areas. Immersing oneself in literature trains the close reader to find hidden meanings, to explore ambiguity and subtlety of expression in small moral moments, such as those that take place every day in the clinical

[77] Ibid., 77.
[78] Ibid., 152.
[79] Barthes, 39.

research center. As Nussbaum suggests, “fine attention to another can make two separate people inhabit the same created world.” In this case, investigators will learn to adopt a compatible language for speaking about the body.[80] Margaret Edson’s “Wit” provides insights into how language shapes one’s moral universe as well as how moral sympathy and the tolerance of ambiguity might lead to the cultivation of moral vision.

As a dramatic work, Edson’s play is full of ethical issues to explore, all within the context of the investigator-subject relationship. Although the protagonist is not a healthy subject but a terminally ill cancer patient by the name of Vivian Bearing, Edson’s play brings out key features of the moral obligation to respect subjects as persons that have substantial pedagogical value. In particular, Bearing’s struggle to maintain a sense of herself as a body-subject goes unrecognized by her physicians as they relentlessly pursue their research questions. In this analysis of Edson’s play I will focus on the dialogical relationship between the clinician-investigators and Bearing. This set of relationships draws on themes of uncanniness and reductionism as they are expressed through language. Dialogical relationships between investigators and subjects are built on two separate lexicons. Each language is anchored to and orientated around the body.[81] However, the moral vision of each lexicon is substantially different. Language as communicated through the body is expressive. It is constitutive of the self that projects into the world. Watching the body language of another when discussing the consent document, handing out medication, or taking a tissue sample is instructive. It should not be ignored. As Bearing’s relationships show, through their lack of attention to subjectivity, “if one really wants to hear the truth of the body, one has to encourage

[80] Nussbaum, 153.

[81] Carl Edvard Rudebeck “Grasping the Existential Anatomy - the Role of Bodily Empathy in Clinical Communication,” In *Handbook of Phenomenology and Medicine*, ed. S. Kay Toombs (Dordrecht: Kluwer Academic Publishers, 2001), 306.

accounts of subjectivity."[82] These accounts are disclosed through language, both verbal and gestural.

For Bearing, language is how she defines herself and her purpose in life. Despite her formidable command of English as a scholar of John Donne's poetry, she is forced to submit the subjective experience of embodiment to interpretation by an unwieldy scientific language. From the beginning, she is at a disadvantage. Several intractable problems of incommensurability plague this kind of boundary work, as she demonstrates in her debate with her oncologist, Dr. Harvey Kelekian, about the meaning of insidious as it applies to her diagnosis of stage four metastatic ovarian cancer. According to the medical plot, it means "undetectable [at an early stage]" but in normal usage it means "treacherous."[83] Bearing emphasizes that this is the correct usage, implying that the medical usage is artificial and wrong as it describes her body's failure to warn her about the growing tumor. Bearing challenges Kelekian's use of the term because he does not explore its nonclinical meaning. For her, the use of the term as "treacherous" likely meant that her experience of her body as an object has surfaced again, this time to betray her. Were he more willing to find out more about her background beyond the superficial indicators of the social status of her professional life, he might have been able to help her process the diagnosis and understand that the only option for medical intervention he was offering was a clinical trial. Instead, he ran roughshod over her and in the process referred to the protocol as both research and treatment.[84] She, of course, did not object as she was so overwhelmed by the news and so unaccustomed to the clinical encounter. As an expert in exegesis, she in fact did use her training to try to explicate the foreign terminology in the language with which she was most comfortable.

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[82] Rudebeck, 307.
[83] Margaret Edson, *Wit* (New York, NY: Dramatists Play Service, 1999), 9.
[84] Ibid., 12.

Bearing tries to enter into a collaborative relationship with the research team by learning their language, but she soon realizes that medical terms are "less evocative" than Donne's prose and poetry.[85] In her desire to know more about her object body, however, she looks up the medical terminology in order to "know what the doctors mean when they … anatomize me."[86] This anatomical metaphor is indicative of her recognition of the reductive power of medical terminology. The language of medical research itself has the power to cut open the body and exacerbates Bearing's experience of the uncanny. Yet, at the same time, she discovers that her clinician-investigators are equipped with a "more potent arsenal of terminology" for describing the body.[87] Against the military precision of their terminology she must build up her own defense. She feels called to play by their rules by speaking their language. In so doing, she denies herself the expressive power of the language of subjective experience. Understanding the medical jargon is essential for making sense of one's biological nature, but the language of medicine is not designed to be evocative, expressive, or even constitutive of subjective experience. To place oneself under the clinical gaze and allow it to dominate one's sense of embodiment is to trade knowledge of the body as lived for knowledge of the body-as-object. It is to objectify oneself, to lose one's self-regard. Losing one's self-regard often results in losing regard for the Other.

Kelekian and his students clearly have lost regard for the Other in their desire to remain detached and objective. Instead of using their skills of observation to tend to the existential needs of their patient-subjects, they treat these skills as mere checklists to be completed. In fact, the term clinical when used to describe the expected comportment of Kelekian and his residents seems fitting in that it implies cold, detached, and highly technical treatment. It is a poor choice of terminology to describe the investigator-subject

[85] Ibid., 37.
[86] Ibid.
[87] Ibid..

relationship in general or any human relationship, for that matter. The term fails to capture the sense in which investigators are to treat subjects as persons while they are responsible for their care under the rules of the protocol. Instead, Kelekian has trained his residents to use the term as a way to remind themselves of superficial steps they believe are needed to relate to the subject as person. Kelekian himself is a model of detachment and efficiency. His relationship with Bearing is superficial at best, lending further weight to the view that he sees her only as a model of the disease he seeks to investigate. He is clearly satisfied with the mediocre performance of his star pupil, Jason Posner, the resident assigned to Bearing's case.

One of the more troubling investigator-subject relationships described in Edson's play is the one that exists between Bearing and Dr. Posner. Posner is cynically interested in human subjects research only because "cancer's the only thing I ever wanted."[88] For him, human subjects are simply models of disease. Cancer is breathtakingly "awesome" in his view because of its ability to proliferate without inhibition.[89] Posner's aesthetic and clinical gaze is fixated on the scientific beauty of cancer as a mysterious intellectual puzzle instead of on Bearing's subjective experience or her intrinsic value as a person. Posner recognizes her only in her instrumental capacity. In one of the more poignant scenes at the end of the play, Bearing is in cardiac arrest. As she lies dying, Posner enters in the room in a panic, trying desperately to save her for science. "She's Research!" he exclaims as he pounds on her chest and tries to resuscitate her.[90] Her primary nurse, the only member of the research team to truly see her as person, fights him off as the code team enters and finalizes the process of fully objectifying her by denying her body a dignified death.

[88] Ibid., 45
[89] Ibid., 46.
[90] Ibid., 64.

Posner constantly forgets that he is supposed to address Bearing directly, but even when he remembers, he does not seem to listen to her or to take her seriously. He seems too busy following the protocol to care about how the treatment is affecting her. Unfortunately for her, both Kelekian and Posner are also incapable of improvising their relationship with her beyond the confines of the research protocol. This inability to improvise may be a product of their own clinical training or it may be a result of their decision to place science above ethics and research results above research subjects. Despite the fact that she is a body-subject, Bearing is seen only with the clinical gaze. Since Posner does not expect Bearing to undergo an experience of the uncanny body, he does not acknowledge these features when they become manifest. The clinical gaze and the language used to construct it cannot accommodate the subjective experience of embodiment Bearing is struggling to express.

Posner sees humanities education as something merely to be endured for the sake of looking good on paper. For researchers like him, it is a "colossal waste of time."[91] Posner, Kelekian, and Bearing all look good on paper, but in the clinical research setting more than intellectual rigor and talent is required. Posner, like Bearing, may have done well in school, but it is unclear whether he has actually learned anything about himself or how to approach the face of the Other. Bearing notes that "the young doctor, like the senior scholar, prefers research to humanity" especially when that research demands directly confronting the raw experience of embodiment.[92] Even his positioning relative to Bearing during his examination of her body is a matter of scientific study. He must position his body in the correct relation to hers as defined by "proxemics."[93] His one-dimensional understanding of medical research as a series of procedures shows through in situations which should not require a scientific understanding to successfully navigate.

[91] Ibid., 45
[92] Ibid., 47.
[93] Ibid., 21.

Like Bearing, he is unnatural in his relationships with others. Both try too hard to remain distant and objective in their approach. In both cases this translates into a kind of alienation and standoffishness that does not allow for real human feeling to enter. While in the short term, working from the baseline towards the goal of medical knowledge about the body with a detached and clinical gaze may accomplish the scientific goals, in the long run investigators are more likely to lose their capacity for fellow feeling. This inability to relate to the Other will eventually make it impossible to recruit new subjects and will contribute to their own burnout. To persist in seeing the body of the Other as a mere instrument of one's own will most likely will lead to the objectification of one's own body as a mere instrument of medical science.

Outside of the hospital, Bearing was a well-respected Donne scholar but within this world, she is treated as just another patient-subject. Travel in this world does not require, indeed does not allow, the disclosure of one's intrinsic and social value. Her accomplishments mean nothing to the radiography technicians. She is not a "force" to them, though she tries to assert herself as such.[94] To her, retaining her subjectivity is more meaningful than anything that can be written on an identification bracelet. She eventually is forced to give up the notion that she is still identifiable as anything more than a research specimen, noting that "I was [a scholar] when I had shoes, when I had eyebrows."[95] With the loss of the integrity of her body image, she has also lost her sense of self. This experience of the uncanny is exacerbated by the clinical gaze, which reduces her to just "the specimen jar, just the dust jacket, just the white piece of paper that bears the little black marks."[96] She feels that if there is to be any afterlife for her, it will be only as a collection of fragments of her intellectual self and the intellectual reduction of her body to pieces of medically relevant academic ephemera that will boost the careers of

[94] Ibid., 16.
[95] Ibid., 54.
[96] Ibid., 43.

Kelekian and Posner. When they write about her, Bearing muses, "the article will not be about me, it will be about my ovaries. It will be about my peritoneal cavity … "[97] Her body-as-object will live forever in the annals of scientific discourse, but her subjective experience will not survive the cutting room floor. The song of her body as it is for-her in these moments of reflection is a funeral dirge, not a New Orleans-style celebratory march. Like the fragments of long-forgotten songs sampled by disc jockeys, she will live on but only in the context of another kind of music. In these moments, the sounds of her body as it is for-the-Other are the upbeat and progressive sounds of science, not the elegant beauty of Mozart's "Requiem" or Arvo Pärt's "Spiegel im Spiegel." The symphony of the clinical research enterprise has no space for elegies.

Given the pedagogical value and the affective power of Edson's play, it seems that this dramatic work would go to waste if it were not made to come alive within the curriculum. One suggestion for bringing the messages of the play home is to conduct a reader's theater production as part of the curriculum. Such a production would help student investigators get a sense of the verbal and gestural language that each character speaks and how it both translates their intentions and affects other characters. If intersubjectivity is to emerge as an expression of bodily empathy, the shared experience of art-making among students will help them develop a comprehensive "grammar of body experience."[98] Such a grammar would have epistemic value in the sense that investigators would be better prepared to integrate subjective experiences of the body into the results of their studies. Furthermore, this grammar of embodiment would help investigators to relate to healthy subjects as they confront the objectification of the clinical gaze.

Taking a cue from the reader's theater exercise described above, I also think there is room within the medical humanities curriculum to incorporate dramatic role-playing.

[97] Ibid., 43.
[98] Rudebeck, 312.

Even though most investigators will likely have little training in the dramatic arts, placing oneself in an encounter with a human subject is perhaps the best way to practice aesthetic attunement. Though the practice of using standardized patients to practice clinical skills of observation, listening, and diagnosis is widespread in medical training, to my knowledge the practice has not been translated into the clinical research setting. By using other students as standardized research subjects, novice investigators will be able to simulate the experience of managing a clinical trial from the informed consent process through the conclusion of the trial. Nonparticipating students can act as an audience and offer their critique of the performance as mock investigators improvise their way through adverse events, uncooperative subjects, and subjects like Nikita, whose bodily intentionality has been adversely affected by her participation in the trial. Students will also have the opportunity to play the role of subjects in order to provide a vicarious sense of subjects' experiences.

RESPECTING NIKITA AS A BODY-SUBJECT

Nikita's story is an amalgamation of the experiences of various actual research subjects. In the spirit of *ad fontes*, which in the parlance of the medical humanities means to return to the original text as a fundamental source of knowledge, students would return to the source of this narrative in order to discover for themselves the features and nuances of the subjective experience of participating in a clinical trial. Indeed, these stories would form the bulk of the required readings. Unfortunately, this body of literature is fairly shallow and uneven in its quality, especially when compared to illness narratives. Nonetheless, there is tremendous pedagogical value in close reading of those texts that are available. In this final section, I will demonstrate the pedagogical value of these stories by exploring some of the central features of Nikita's narrative. My aim in this interpretation is to provide a model for how the ideal clinician-investigator should approach Nikita as a body-subject.

When we last left Nikita she was struggling with issues of bodily intentionality and objectification. She was enrolled in a sixty-day microgravity study and had some questions about her experience of participating in the clinical study that were related to her sense of embodiment. Her difficulty in dealing with these issues was compounded by the lack of interlocutors to speak with--besides the research nurses who were attentive to her physical and emotional needs, but who did not seem to understand her existential questions. Although at first she enjoyed being referred to as a "flight analog," over time the appellation began to wear on her. She felt that it was symbolic of the way that the clinician-investigators and most of the research team saw her. It felt odd for her to be called a flight analog when she was confined to a bed. For her, this lack of bodily intentionality was disturbing. Giving up her active lifestyle and the pride she felt in maintaining a body schema that expressed her youth and vigor was humiliating. She felt powerless to modify her environment, which made her body seem that much more uncanny. As each day passed, she felt more and more like she was losing equilibrium with her environment. Her inability to surpass her body towards her own possibilities was exacerbated by the panoptical vision of the research study monitors. Responding effectively to these symptoms of the objectifying gaze (in the Sartrean sense) is essential to showing respect for persons. In order to mitigate the objectifying effects of enrollment and participation in research protocols, investigators should use their skills of aesthetic attunement to reflect on how the elements of instrumentality, docility, and the denial of subjectivity become inscribed in the clinical gaze. Deconstructing the clinical gaze is the first step towards acting on the obligation to respect persons as body-subjects.

In order to build an improvisational ethic that is responsive to both epistemic and moral values, investigators must first bracket the clinical gaze. To *bracket* in the context of the face-to-face encounter means to hold in abeyance the metaphorical representations of embodiment described above. By bracketing the clinical gaze, investigators allow their skills of aesthetic attunement to surface in order to search for the subjectivity of the

human being standing before them. Dialing back the clinical gaze makes room for a dialogical relationship to emerge that is responsive to the call of the Other. This task of bracketing and softening may be made simpler by considering these metaphors in the context of an idea borrowed from art history. Michael Baxandall refers to the *period eye* as the "stock of patterns, training in a range of representational conventions and experience, drawn from the environment as we search for plausible ways of visualizing what we have incomplete information about."[99] The period eye of artists is formed by the general cultural milieu as well as the environment in which they create art objects. Investigators as creators of scientific objects are also shaped by the culture of clinical science, practice of medicine, and the zeitgeist of the age in which they live. Investigators are trained to see the body-as-object from the set of stock patterns they inherit from their training as scientists. By increasing the diversity of this stock and enlarging the range of representational conventions, investigators' aesthetic attunement might also be enlarged. The first step in developing a response to Nikita's struggle with bodily intentionality is to bracket the clinical gaze by considering how the period eye objectifies bodies. In other words, in order to bracket the gaze, one must first identify the range of its vision.

Following Bruno Latour, T. Hugh Crawford argues that human bodies are "quasi-objects—hybrids that participate in both natural and social realms by circulating, sometimes unnoticed, in networks that are also both natural and social."[100] Crawford advocates for a mapping out of how knowledge is produced along socio-political and cultural lines, taking into account the rhetorical foundations of knowledge production. The production of scientific images places human bodies in this hybrid position as it depends on the rhetoric of reductionism to both justify the image and to place it in its "proper" context as a scientific object. The aim of scientific images is not to provide a

[99] Onians, 179.

[100] T. Hugh Crawford, "Imaging the Human Body: Quasi Objects, Quasi Texts, and the Theater of Proof," *PMLA* 11, no.1 (January 1996): 67.

spectacle that provokes self-reflection and undermines metaphorical understandings of the body, but to provide confirmation of a hypothesis and thereby increase knowledge. Yet, these images have the effect of appropriating the image "—and even the living or dead tissue—of the person turned object, disempowered and converted into object; reshaped, reinterpreted, reinvented—and all beyond the subject's control."[101]

In his analysis of the radiological iteration of the clinical gaze, Amit Prasad indicates that in the search for pathology or in the desire to normalize, the body is "made notational (i.e., converted into sets of isolable, disjoint, and differentiable parts)."[102] Vision is narrowed to the search for pathology, much in the way that moral vision is narrowed by the rhetoric of reductionism. Radiological vision, or what Prasad calls "cyborg visuality" is part of the rhetoric of reductionism insofar as it seeks to standardize the body as a working object.[103] Although he is referring to MR images of the body, Prasad's argument would equally apply to the Dexa Scan images used during Nikita's study insofar as each form of medical imaging makes the body notational. Through this process, "all that cannot be accounted for is removed and different parts that constitute the image/body are clearly marked out."[104]

Scientific images are addressed to a different knowledge community and therefore conceal the political, social, cultural, and existential factors that contributed to the production of the image. Unraveling the fabric of these hidden factors is integral to reforming the clinical gaze since doing so lays bare the rhetoric of reductionism. The clinical gaze serves a discursive function as part of a rhetoric that persuades clinicians and the public that the image is "interchangeable with the real thing depicted instead of a

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[101] L. Schwartz, "Parallel Experience: How Art Can Inform Human Research Ethics," *Medical Humanities* 29, no. 2 (December 2003): 62.

[102] Amit Prasad, "Making Images/Making Bodies: Visualizing and Disciplining through Magnetic Resonance Imaging," *Science, Technology, and Human Values* 30, no. 2 (Spring 2005): 293.

[103] Ibid., 291.

[104] Ibid., 307.

construction of it" by omitting the facts of its production from the discourse.[105] Interpreting these images as interchangeable with real body-subjects perpetuates the view that the body should be treated as a working object. What better way to reify the mechanical metaphor than to persuade investigators that machines are ideally positioned to provide objective knowledge about the mechanical body. Deconstructing the visual rhetoric of scientific images and replacing those metaphors that dehumanize subjects with metaphorical representations of embodiment that recognize the instrumental *and* intrinsic value of persons is also essential to reforming the clinical gaze. As an example of how investigators might learn to bracket the clinical gaze and address subjects' experience of participation in clinical studies, I offer the following brief dialogue between Nikita and the clinician-investigator in charge of her study.

> Nikita: I just talked to psych. They don't seem to understand what's going on with me. I'm really excited about the project. And lying around watching *Star Trek* reruns all day is tons of fun but … I feel like some kind of circus sideshow freak. Always being watched by somebody. No privacy … my body feels all out of whack. It's really starting to bug me.
>
> Dr. A (matter of factly): Well, your blood volume is shifting in response to the alterations in your body's alignment. It's having difficulty adjusting, but all of your tests have come back within normal parameters. We've tried to give you as many recreational opportunities as we can, but we're limited by the protocol, as you know, in terms of how often we can allow you to leave the ward, how far up you can sit, etc. All of this should have been explained to you at the initial briefing.
>
> Nikita: It was and I understand the biological aspects of what's going on. You've done a good job of explaining the physiological components of my situation, but the numbers don't mean much to me. I'm just frustrated by not being able to move around. I thought I'd be able to just pretend I was on some weird reality show or that I'd be able to just think about the money and everything would be fine. But it's not.
>
> Dr. A: Well, I've seen a lot of folks come through here that felt the way you do. It seems like moving around, working out, being sociable is really important to you … For example, I can tell you miss being out in the sun.

[105] Kelly Joyce, "Appealing Images: Magnetic Resonance Imaging and the Production of Authoritative Knowledge," *Social Studies of Science* 35, no.3 (June 2005), 440.

> Luckily the water has been really choppy recently so you haven't missed out on any killer waves. And the study should be over in time for you to wax up and head out.
>
> Nikita (a bit surprised): How did you know I was a surfer? We've never talked about it.
>
> Dr. A: The tan lines on your wrist and ankle suggest that you spend a lot of time bodyboarding and have just graduated to surfing. Some parts of your hair are lighter than others, but there's no sign of intentional highlighting which suggests that you've spent a lot of time outside, possibly in salt water. The relaxed way you carry yourself suggests someone that has spent time traveling and enjoying life. The fact that you've mentioned participating in other trials, mainly around coastal areas also supports the hypothesis that you're into watersports and that clinical trials may be the means by which you support yourself. Given all that I can understand why this trial must be particularly hard for you.
>
> Nikita: Yeah, I've thought about dropping out, but I really need the money. Surfboards don't come cheap and I'm saving up for another trip out to Cali.[106]

As the dialogue above has illustrated, a second response to Nikita's predicament involves recognizing the impact that reclining for an extended period of time has on bodily intentionality. One of the most significant features of Nikita's experience of embodiment is the confinement of her body into a supine or prone position. The removal of the possibility of an upright posture is more than a mere inconvenience; it is a kind of dehumanizing demotion from the world of projects. Following E. W. Straus's philosophical and anthropological research, Wim Dekkers notes that the upright posture permits humans to establish a safe "distance from things, which allows us to confront those things and look at them from afar." [107] More importantly for Nikita's purposes, this posture affords "distance from our fellow human beings which permits us to meet others 'face to face' in various social relationships." In fact, until the advent of the Internet, the face-to-face encounter was a prerequisite for genuine human relationships. Conversely,

[106] This is a purely fictional dialogue that I created to illustrate the practical application of aesthetic attunement in the face-to-face encounter.

[107] Dekkers, 119.

standing over a prostrate person is often interpreted as invoking a relationship of dominance. Standing upright initiates a relationship of equality. Furthermore, in Nikita's case her inability to stand upright limits the possibility of her freedom. Linking posture to bodily intentionality, equality, and freedom in this manner is an example of how an aesthetic judgment, based on a theory of perception that uncovers the symbolism inherent in the figural relationship of the body to a particular context, leads to reflection on the moral implications of bodily intentionality and gestures.

Part of the bodily intentionality afforded by the upright posture is the power to transform seeing into beholding.[108] Animals and other members of the kingdoms of organisms are able to see, but humans are able to behold one another. This is the kind of moral vision that is both deep and broad. Investigators need to go beyond seeing the body to beholding the subject. To behold the Other is to show the Other reverence through vision. It is to hold the Other in "contemplative regard."[109] Beholding is expansive. It offers 180 degrees of vision that operate from a distance. It is also part of scientific discourse in that the etymology of the word *theory* is derived from "theorein" or "to behold." In Straus's view, "distance is the condition for seeing the other as other in his uniqueness."[110] Distance provides insight into the essence of the Other without committing oneself to the gaze or to dialogue. Unlike four-legged animals, whose sight is aimed towards the ground, "the eye of man, emancipated from the bondage of catching, grabbing, and gobbling, can dwell on the things themselves."[111] Yet, Nikita is not able to behold others. Her eyes are cast to the ground, to the level of a child who is not able to walk. Her bodily position has caused her bodily intentionality to retreat to the level of childhood perceptive capabilities.

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[108] Ibid.

[109] Ibid.

[110] E.W. Straus, "Born to See, Bound to Behold: Reflections on the Function of Upright Posture in the Esthetic Attitude," in *The Philosophy of the Body. Rejections of Cartesian Dualism*, ed. S.F. Spicker (Chicago, IL: Quadrangle, 1970), 342.

[111] Straus, 341.

While the idea of showing reverence for the body-subject may seem out of place in a secular world, the connotation of the word speaks to an attitude that recognizes, reciprocates, and hesitates to disturb body-subjects. To show reverence is not necessarily to worship the body, but to demarcate it as intrinsically valuable and not to be disturbed without a noble purpose in mind. Persons who show each other reverence recognize that they have entered into an I-Thou relationship. According to the theologian Martin Buber, "in I-Thou relationships, whole persons encounter each other as beings who are present to each other."[112] Showing reverence for the body-subject is first and foremost about recognizing the presence of the subjectivity and the personhood of the subject. I-Thou relationships differ from I-It relationships in that the latter are "characterized by detachment from the other, by use of knowledge about the other to categorize the other and to treat the other in a standard way, and by objectification of the otherness of the other."[113] In the former, the otherness of the Other is the primary value that sets forth all other moral obligations. It is a fundamental reverence for the alterity of the Other that forbids me from harming him. Seeing the Other is seeing the possibilities of another body-subject, opening oneself up to observation and dialogue with that body-subject and taking a "special regard for the particular person in a concrete situation."[114] However, there are institutional obstacles that may prevent investigators from entering into I-Thou relationships. Anne Bishop and John Scudder have invented a third option that combines professional detachment with personal presence.

In the I-It (Thou) relationship, investigators commit to "deal[ing] with other persons objectively but, at the same time, to treat[ing] them with the dignity and respect due a person" built on maintaining an awareness of their subjectivity.[115] This is the kind of moral vision that training in aesthetic attunement provides. Aesthetic attunement in the

[112] Bishop and Scudder, 45.
[113] Ibid..
[114] Ibid., 49.
[115] Ibid., 46.

context of showing respect for persons is about finding a balance between the scientific uses of the body and awareness of the person as body-subject. Neither side of moral vision may be permitted to dominate the other, yet on the whole the balance should shift towards respecting persons. The weight of the investigator-subject relationship is not on the quality of the science, but on the quality of the relationship of one human being to another.

There are several objections that one might raise, most of which challenge the assumption that aesthetic attunement and the cultivation of moral vision will lead to changes in the way that investigators treat subjects. First, given the lack of evidence supporting change in behavior among physicians when introduced to a similar program of study, why would investigators be any different? Most of the reports in the literature are based on successes and failures in medical education or in the responsible conduct of research program, which tends to focus on issues in biomedical publication, data falsification, protecting privacy and confidentiality, and whistle-blowing. The approach I have described above is qualitatively different. Instead of opposing scientific ways of seeing as inherently dehumanizing, the metaphorical foundation of the aesthetic approach incorporates science as an aesthetic practice. Silvia Quadrelli, Henri G. Colt, and Guillermo Semeniuk reported some successes in using film studies to provide "course material that encourages an appreciation of the aesthetic [that] might certainly craft a more thoughtful, aware, and sensitive person."[116] Furthermore, the lack of definitive empirical evidence neither proves nor disproves the claim that broadening the moral vision of investigators would help expand their understanding of what it means to respect persons.

The second objection one might raise is the suggestion that there is a paucity of evidence supporting the positive influence of aesthetic education on moral development

[116] Silvia Quadrelli, Henri G. Colt, and Guillermo Semeniuk, "Appreciation of the Aesthetic: a New Dimension for a Medicine and Movies Program," *Family Medicine* 41, no.5 (May 2009): 316-319.

because the "arts only influence those already open to them."[117] One response would be to reiterate the idea that scientific and aesthetic vision are composed of the same elements. Art breaks the "'skin of things' to show how the things become things, how the world becomes world."[118] Both scientific and artistic images of the body construct the shape of investigators' moral vision by breaking through the skin, revealing the depth of the flesh of the world. As Joseph Herman explains, "selectivity, problem solving, curiosity, observation, the ability to turn a seemingly remote or irrelevant association into a discovery, and an attempt to come to grips with humanity's state are hallmarks of both."[119] The methodological commonalities between art and science suggest that some investigators are already open to art because they already have some training in these methods. It is also clear that scientists have begun to embrace the kind of systemic thinking found in the translational science paradigm. Basic scientists in particular are learning to see how their work may serve to structure how the problems of clinical medicine are framed and tested experimentally.[120] In this sense, the metaphor of the body as music may help to shape the epistemology of science by helping basic scientists understand their word as part of the symphony of medical innovation. Furthermore, it is not too difficult to defend the claim that some scientists in other fields have found the search for beauty to be a strong motivator for their discoveries.[121]

A third objection to the curriculum might ask: Why would an investigator need to take additional courses when it is more than likely that any clinical scientist can be

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[117] Macneil, 86

[118] Merleau-Ponty, 181.

[119] Joseph Herman, "Medicine: the Science and the Art," *Journal of Medical Ethics: Medical Humanities* 27, no.1 (June 2001): 43.

[120] S. Wutchty, E. Ravasz, and A. L. Barabási, "The Architecture of Biological Networks," in *Complex Systems Science in Biomedicine*, eds. T.S. Deisboeck and J.T. Kresh (Berlin, Germany: Springer, 2006), 165-181.; and Borja Esteve-Altava et al., "Network Models in Anatomical Systems," *Journal of Anthropological Sciences* 89 (2011): 175-184.

[121] Michael Dickson, "Beauty Doth of Itself Persuade: Dirac on Quantization, Mathematical Beauty, and Theoretical Understanding," in *Discourse on a New Method: Reinvigorating the Marriage of History and Philosophy of Science*, eds. Michael Friedman, Mary Domski and Michael Dickson (Chicago, IL: Open Court, 2010), 405-422.

morally aware, responsive, and deliberative without aesthetics? While it is certainly possible, it is unlikely that any particular investigator would be able to truly respect persons if his moral vision is shaped by metaphors that objectify, dehumanize, or degrade the human body. Furthermore, like any discipline, medical research needs critical voices from within the discipline to hold investigators accountable for the kinds of ethical violations described above. Training in the medical humanities gives investigators this critical edge, provided that they are willing to "accept that provocation and discomfort … play a valuable role in learning."[122] It should also be noted that an investigator cannot simply rely on his aesthetic sensibilities to serve as moral guides. Aesthetic attunement is only fully developed if one's moral vision is attuned to the other and keenly focused on developing an ethic of recognition, reciprocity, and respect. The development of skills of perception and aesthetic judgment is meant to develop the capacity for recognizing the moral obligation to respect others. Aesthetic judgment serves as a means for developing skills of moral reflection, but practical action must still satisfy the requirement to show respect for persons. When one's goal is to cultivate moral vision, aesthetics without moral judgment is like eloquence without wisdom.

These kinds of questions will remain as long as medical science and medical humanities continue to speak different languages. Coming together to consider how best to describe the body is the perfect forum for building a dialogical relationship between clinical investigators and medical humanists. Paul Ulhas Macneil argues that there "needs to be a shift in the foundational assumptions of medicine and the metaphors by which medicine is taught if the arts and humanities are to contribute more fully to medical (and other healthcare) education."[123] The opportunity for this kind of shift has already presented itself in the form of the translational science movement. In the conclusion I will provide some suggestions as to how to take advantage of these opportunities.

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[122] Macneil, 86.
[123] Ibid., 89.

Conclusion

Much has been written about the moral obligation to respect persons. As I have mentioned throughout this dissertation, this literature has almost exclusively been limited to debates about protecting and respecting autonomy. As I continued to examine the literature, I realized that there was something missing. To my mind, there is much more to being human than simply being an autonomous and rational being. Phenomenologists have done the most thorough job of articulating how to discover the essence of personhood, yet they have neglected to use their methodology to explore how medical researchers understand some of the central features of personhood: embodiment and subjectivity. For too long, human subjects have been used as mere means by investigators, often without malicious intent or even an understanding of how medical research can objectify bodies. While the temptation for some investigators may be to interpret this dissertation as an unjustified attack on science or as an impractical suggestion for investigators to visit more art museums or spend more nights at the theater, the message of this work has been focused on bringing science, ethics, and aesthetics together in a common purpose. The majority of modern clinician-investigators entering the field have no intention of harming research subjects. Yet, somehow in their attention to the scientific goals they chose to pursue, subjects were harmed. Developing an educational system that rewards and encourages investigators who are able to be competent scientists and fully respect those volunteers who have agreed to participate as partners in these endeavors is a goal that serves both science and humanity in general.

Translational research appears to be one area in which a novel research ethics methodology such as the one proposed in this dissertation might thrive. Although there is no real consensus about how the translational research paradigm is to be understood, the model that I am most familiar with places the translational work between the boundaries of basic, clinical, and community research projects. Most of the general discussion about translational research ethics focuses on the core competencies in clinical and translational research. While most of these core competencies focus on scientific methodology and the protection of the integrity of medical research, there are areas of competence that deal directly with human subjects protections. For instance, part of the clinical interactions competency requires investigators to describe the "fundamental principles of the protection of human subjects, the main authoritative bodies, key codes, and scope of enforcement."[124] These principles must also be incorporated into the research proposals as well as the actual conduct of the trial. Providing investigators with the means for expressing the capacious sense of respect for persons outlined in this dissertation will not only satisfy but also substantially exceed the core competency requirements. However, the ability to merely describe this fundamental principle is not enough. Investigators must be able to develop their moral vision as an overall framework for designing, conducting, and disseminating research.

Aesthetic attunement and moral vision are well-suited to addressing the ethical gaps in translational research. Integrating a curriculum that develops these capacities as part of the core competency requirements discussed above will help bioethicists and

[124] National Center for Advancing Translational Sciences, Education Core Competency Work Group, "Core Competencies for Clinical and Translational Research" (July 14, 2009) https://www.ctsacentral.org/education_and_career_development/core-competencies-clinical-and-translational-research

medical humanists reach a core demographic within the research community. Furthermore, with a more capacious sense of how to recognize ethical issues in medical research, investigators will be able to satisfy and, in fact, exceed these core competencies.

As more basic scientists are trained to think like clinical researchers, the demand for more bodies to participate in clinical trials will increase. This aspect of translational science offers additional collaborative opportunities for patients and subjects to "become actively involved in breakthrough science."[125] In a recent survey and focus group-based study, researchers found that subjects' interest in participation and collaboration was driven to some degree by the personal relevance of the research.[126] While studying the retention rate of research subjects, Rhonda Kost and colleagues discovered that this rate was affected by the level of subjects' personal interests in the research as well as the quality of the relationship that develops between subjects and the research team. While personal interest may be a motivating factor for enrollment, research subjects are more likely to complete research protocols if they feel they are respected by the research team.

The survey also indicated how limited a role the informed-consent document plays in subjects' decisions to enroll. Far more important to subjects is the relationship that coordinators and investigators establish with the prospective subject. This relationship determines in part whether subjects feel institutional pressure to enroll or are at all fearful of the process. Investigators who took part in the survey also commented on the importance of the relationship. The importance of the face-to-face encounter remained paramount as a general measure of the experience of participating in the trial

[125] N.C. Kemaris et al., "Translational Research: from Benchside to Bedside," *Injury: International Journal of the Care of the Injured* 39, no.6 (June 2008): 644.

[126] Rhonda Kost et al., "Assessing Research Participants' Perceptions of Their Clinical Research Experiences," *Clinical and Translational Science* 4, no. 6 (December 2011): 403.

itself. As a measure of the importance of the encounter, feeling respected and valued was viewed as very important to subjects as was the closeness of their relationship with the research team.[127]

Besides being invested in a caring and professional investigator-subject relationship, subjects also felt investigators valued them when they shared research and clinical results.[128] One way of showing respect for the subjectivity of the Other is to continue the dialogue with them after they have completed the trial. Providing clinical results to subjects during the trial helps them to balance their feelings of objectification with insights into how their bodies operate normally and while under the influence of the intervention. Such information would help them deal with their uncanny bodies as long as investigators are able to help translate the medical jargon into terms that can be understood and easily assimilated into subjects' reflections on embodiment. By way of analogy, denying subjects research results at the end of their participation in the trial is similar to denying studio musicians access to the finished recording. Both parties want to feel as if their contributions have mattered because feeling useful is important for the self-image of subjects and musicians. Otherwise, subjects may feel as if they have simply been used for the ends of investigators or that their contribution is so insignificant that sharing the results of the study would not be worth investigators' time.

Another area of translational research that may benefit from the ethical and epistemic framework I have outlined above is the T3 area. In this area of knowledge production, innovations that have successfully been translated into clinical practice are reevaluated relative to metrics of patient care and community health. At this stage of

[127] Ibid., 408.
[128] Ibid., 411.

development of an intervention, the public-health implications are beginning to emerge along with opportunities for collaborative partnerships between communities of individuals and clinicians. While the normative obligation to respect persons I have outlined was not designed as a way to show respect for communities, there may be a way to apply these ideas to small communities. Moral vision on this scale would involve training public-health investigators to develop their ability to treat members of a community as more than just informants. The dialogical root of respect for persons would be at the center of any program of community-based participatory research. Indeed, this is also part of the cultural diversity requirement for the core competencies. To satisfy this core competency, investigators must be able to "recognize the demographic, geographic, and ethnographic features within communities and populations when designing a clinical study."[129] It is in this area of research ethics that investigators would need to be attuned to how to avoid seeing bodies as factories of knowledge production. The dehumanization of communities is as real a threat as the dehumanization of individuals. However, community-based participatory research is predicated on the idea that communities and investigators will form collaborative partnerships. The core competencies expected of translational researchers focus on building these partnerships by requiring training in cultural competency and community engagement. This commitment would seem to mitigate the harmful effects of any reversion to the industrial metaphor. Learning to be aware of how harmful these metaphorical representations of communities can be is part of the goals of the curriculum described above. Yet, the expansion of this curriculum and

[129] National Center for Advancing Translational Sciences, Education Core Competency Work Group, "Core Competencies for Clinical and Translational Research,"3.

its integration into the ethics of translational research is only one possible direction for future research.

The stories of professional research subjects' experience remain, for the most part, unwritten. In the conclusion of their qualitative study, Kost et al. point to the dearth of information on subjects' experiences. Those who have studied subjects' retention rates and experiences qualitatively have tended to favor the use of "process indicators" like signed informed-consent forms, instead of focus groups and surveys.[130] I hope that in the future more bioethicists and medical humanists will generate studies that explore the "emotional, cognitive, and sensory experiences that accompany research procedures."[131] In particular, documenting and evaluating the sensory experience of participation in research studies is integral to establishing how research subjects view their experience of embodiment. Future studies should formulate research questions around these experiences. In addition, more work needs to be done outside the realm of medical research as it is practiced at academic medical centers. There is an entire subculture of self-anointed "professional guinea pigs" who travel the country looking for research trials that pay well with minimal risk. Although Roberto Abadie's *The Professional Guinea Pig: Big Pharma and the Risky World of Human Subjects* is an excellent first step, it was written from an anthropological perspective and so was fairly light on ethical analysis. Nonetheless, medical humanists have a unique opportunity to learn from Abadie and journalists like Eileen Welsome in order to explore the murky side of research ethics. Now that a substantial portion of clinical research is occurring without NIH funding, those commercial organizations that do not take federal monies are living in a Wild West,

[130] Ibid., 409.
[131] Ibid.

free from the kind of strict regulation and oversight that characterizes academic medicine. Who is watching over these investigators and subjects? Will the kind of curriculum proposed above address the problems inherent in private research enterprises? These are questions that remain open to investigation and should prove fruitful avenues for future research.

In this dissertation I have connected a number of moral and epistemic values and norms as constitutive of moral vision. To my mind, those who are under the moral obligation to respect persons must hone their skills of aesthetic attunement in order to produce moral vision that is broad, deep, clear, and firmly fixed on the Other as body-subject. Excellent moral vision is necessary for recognizing ethical problems before they become overwhelming. Moral vision is enhanced by a discourse that encourages investigators to respect the intrinsic value of persons and to put people before science. Seeing the intrinsic value of aesthetic objects translates into seeing the intrinsic value of persons. Intrinsic value is more easily perceived if the investigator as moral aesthete is guided by a rhetoric that identifies the many metaphorical representations of this value. Metaphors serve as guidebooks for the scientific journey that investigators have chosen to undertake. Yet, they can lead the unsuspecting traveler astray, which is why these guidebooks need to be updated by those who are more familiar with the terrain. Subjects can serve as expert guides for extended tours of their own bodies as well as the hinterlands of their subjective experiences of embodiment. Investigators must also be willing to blaze their own path, to improvise along the way in order to meet subjects where they live. Respecting persons means finding the ground of intersubjectivity in the

shared experience of embodiment. Both clinician-investigators and human research subjects deserve to be respected as persons.

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