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Knowledge, Ethics, and the Fetus-as-Surgical-Patient:
Articulations of Legacy and Frontier

by

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I. Prelude

The ethical axes around which I am drawn in these nascent days are not so much those of technological implantation, of whether artificially sustaining or ending life are appropriate or "ethical", as of self-reflection, as of reconfiguring the modes of knowing and being which I adopt in this moral space of uncertainty that is medicine. I am engaged, constantly and self-reflexively, in a discourse with myself and the world in an effort to locate and follow a thread of something which I might call meaning. Having chosen medicine as my life's vocation, I wonder still, "why?" For, in this milieu of technological embellishment, I cannot accept on faith, willingly, the principle of healing above all else.

I am unable, freely, to jump past the primordial questions which haunt my every step: At what orientation do I stand in apposition or opposition to health and illness, life and death? To what degree should I rely uncritically on the vast, but basic, apparatuses of knowledge production which increasingly complicate the "science" of human being? How do I prevent the prerogatives of privilege and power from circumscribing me, trapping me in their web, while still making constructive use of them? How does the structure of health care in America, and the underlying drives which have shaped and continue to shape it, lock me and society in to a perpetuation of more of the same? How do I balance the being and becoming in me?

*A commensurate donning—
this coat of white,
which matches
my skin
and hugs the hill of my shoulder—*

Moving beyond 'good' and 'evil', beyond the simple yet stultifying hegemony of binary conceptualization, I must discern in my action an unopposed, incontrovertible

reservoir of meaning. Elsewise, I become mired in the accretion which settles, again and again, in the cleft that opens with the fracture of meaning inevitable in a matrix of binarism. However, I am aware that such a discovery is not forthcoming. To remain focused, in futility, on the task of elucidating the truth and secret of this layer, is to deny myself access to the domain of action—to posit action without some conviction of purpose, though, is to risk misguidance: thus am I rendered mute. At some point, I must accept multiple heuristics (indeed, I have accepted many already); how and where?

In considering the thesis project to which I will devote myself, my task will be, at heart and on the surface, a discursive journey. As I look into and through various moments on the periphery of the window of medical knowledge and practice, in something of a multifaceted "triangulation", I will be looking into myself simultaneously. In large part, my electing to make of my thesis project such a patently personal exercise is a step (though not the first) in the journey which I will endeavor to record in it.

One of the major dilemmas I have encountered in considering what to do with this opportunity concerns the problem of problematizing in research and in general. I am struck by the discord which resounds in my search for truth, my quest to understand: in choosing a topic, I must necessarily limit what I observe, I must accept that the infinite complexity of most anything I might imagine can be suspended, and a problem (the notion of which reflects an ingrained bias toward normalization) explored in relative isolation. What limits can be imposed on a project reasonably? In most every endeavor, there is some point of heuristic suspension: I will begin "X" here, accepting numerous assumptions and premises which merely recognizing "X" as "X" entails, which setting "X" in relation to anything and everything else, assigning to "X" a context, not to mention working with "X" as a reified object of analysis, inevitably engender.

*a currency
I would
but would not
shed*

As inseparable dimensions in the process of knowledge production, the performance of research and its written presentation share the inherent dilemma of how to do or say without at once circumscribing and eliding, reifying and disenchanting. Though this might seem to suggest something underlying which is there to be profaned in its limitation, some something of which a signified can be divested, it is more urgently a challenge to myself to create something less

fettered by structure and method. For, insofar as it is in the very attempt to define that any possibility of limitation or infinity is acknowledged, I must seek liberation not in abstract definition, but in a more self-aware process of internalizing difference.

Maintaining my belief in the intertextuality of knowledge (medical, scientific—indeed, all), in my thesis I hope to set up an implicit parallel between the performance and presentation dimensions of knowledge production. Of course, even in writing about the limitations of writing, there is a reliance on the written, an inevitable separation of that which is, and that which is not, included. The

*Beneath the vestments
of this (my) chosen path
what is it
most naturally?
that resides—*

task: a strategic employment of such limitations as a means of forcing self- and alter-exposition. In my

project, I will talk about many issues of power and knowledge, with questions of vision, image, and representation laced throughout. I will ask, inter alia, whether the schematic innervation of the epistemic field, the body of constructed reality, has not become dependent on the production of image, on a visual reification of the microcosmos of the medical object; whether, if so, this reliance on the visible and metaphors of the visible does not constitute an intractable boundary to be traversed in the production and legitimization of medical knowledge; and,

again, if so, what the implications of this orientation might be. But at the same time, I will utilize, consciously and extensively, a metaphorical framework which is, itself, highly visual in nature. Will I undermine myself in so doing? To a degree, perhaps. But I hope to minimize this necessary elision stylistically, interweaving discussions of science and the clinic with theoretical observation and analysis, poetry and evocation, all against a vast backdrop of silence and erasure—I will call it my poetics of anamorphosis.

I envision in this approach an opportunity to exploit and confuse the mechanisms on which and the tools with which I work—language, knowledge, and their necessary limitations—to circumvent, heuristically, the heuristic strictures of focal inquiry. I will celebrate and deride at once the many multiplicities in language, strive to avoid patterned rendition, to shake my style free of any underlying (and undermining) consistency of form. I will attempt to make clear in every sentence that my sentences, and the thoughts and feelings that they represent, are not clear; that there are multiple meanings and purposes flowing through my every word. Likewise, though tempted, I will not attempt to explain my method fully—it will be engendered only by reference to itself, sporadically and whimsically, as one aspect of its invigoration, even in involution. Moreover, just as I will resort to the segregation of certain words within quotation marks, as if to suspend from judgment and

disavow all that might seem imperfect or objectionable in them, and in the process to exonerate myself, in other instances, I may find occasion to elaborate in a footnote on such words and the various threads which intersect in them, and, more frequently than either of the above, I imagine, I will simply let them stand alone.

For the purpose of this report, I ought to mention that the questions/issues whose trajectories I intend to *observe* (though not necessarily *record* in writing), focusing most pointedly on the

intersections between and among them, may include: possible instabilities in the quantitative, probabilistic/statistical, and visual biases in

*Is the inevitable
violence
of its forging
and upkeep
one*

*of creation?
undoing?
involution?
restoration?*

knowledge production; the rhetoric, logic, and perspective of NIH technology and research assessment; the operations and agenda of the physicians and researchers at the UCSF Fetal Treatment Center; social and epistemological implications of macro- and micro-imaging technologies; the making and molding of social dynamics as medical issues. As moments in the field of power in which "medicine" is located, they are representative (in a limited way) of the infrastructures which coalesce to constitute the window of medical knowledge and practice. As an individual, how will I configure myself ethically within this system?

II. Frontier Legacy

What landscape unfolds before me, I wonder, as I shuffle through the rote and routine of my first-second-third year of medical school. Plodding through the blustery haze of becoming, the (per)formative exercises of indoctrination that found my medical education, I search for an ethical center—one without the axis of ego. In this dizzying age of technology, of textbooks embellished with the inveigling gloss of images mechanically born and bred, I am awash in light, in biological and pathological truth revealed to the eye. The allure of literal bodily insight, such as allowed by the vast repertory of imaging technologies, impels in me an instinctive resistance, one which I want to believe is somehow noble, as the perceptual modality it obdures.¹ Yet, ironically, I seem determined to configure my resistance within a metaphorical space of visual definition and elaboration.

*a dichotomy
of perceptual reinforcement
streams
from the experience
of human dissection*

¹See Hans Jonas, "The Nobility of Sight: A Study in the Phenomenology of the Senses, in *The Phenomenon of Life: Toward a Philosophical Biology* (Chicago, 1982), an illuminating essay in which he argues that, "Since the days of Greek philosophy sight has been hailed as the most excellent of the senses." (p. 135). Martin Jay, *Downcast Eyes: The Denigration of Vision in Twentieth-Century French Thought* (Berkeley, 1993), offers a rich look into the place of vision in Western thought; though I make no further references to this work, it has served as a fertile source and context in my exploration of some of the thoughts that follow, as well as many that do not. Also, I might take this opportunity to address some of the stylistic idiosyncrasies of which I have availed myself thus far, and

"Medicine", as I draw it in my mind, exists as a window of knowledge, and the practices it engenders and finds sustenance in, in the infinite field of possibility. It is formed as a matrix, forever in flux, of innumerable intersecting moments, through which a vision (or illusion) of clarity shines, enabling orientation and action. Just as the window itself is constantly shifting, the fabric of the universe in which it is cut cannot be anchored—the scope of both, one within the other, changes daily. However, the domain encompassed within this theoretical visual space does not simply expand, for the relentless advance of "progress" is coupled with a convergence: with equal facility it wields the sword

with which it slashes
frontiers of its
royal mantle, a cloak
casting back into the
making mere legacy

*With every step,
atresiac bands
of a becoming dislocation
tighten*

away at the unexplored
domain, and the train of its
which it drags behind,
void of silence—and
of—that which, once clear,

will continue to avail myself: my frequent use of the passive voice, and of apparent anthropomorphism, though perhaps indicative of a stylistic rut into which I have worked myself, are deliberate tendencies that I see as 1) part of an understated effort to divest characteristically subject-less scientific language of its pretextual objectivism, and 2) a distancing of my thoughts and feelings from the I/eye which I so distrust. Furthermore, in a deliberate attempt at evocation, I will use words (e.g., obdure, pretextual) as parts of speech which, according to standard English, may be incorrect or improper. In addition, my footnotes may be extensive (though hopefully not prolix), for this associative expansion of the central text is the element of my writing that I believe, ironically, most fully lends it intersubjective coherence.

is not so any longer.²

*against the resistance
of this will which
pulls me along*

As I strive to gaze into and through this window, to make of it a mirror and crystal ball, it is the edges, the flickering shadows in which progress is negotiated, that capture my

interest.³ Lingerin there, amongst realities and truths on the verge of assimilation or exile, I⁴ find myself in the protracted midst of a major

²Immediately following the sentence quoted in the above footnote, Jonas writes, "The noblest activity of the mind, *theoria*, is described in metaphors mostly taken from the visual sphere." (p. 135).

³It is thus (in part) that I am inspired by and drawn to the writings of Nietzsche, whose subtle challenges to the Enlightenment metaphysics of presence, through form and transformation, underlie my own effort. Resilient critique of Hegelian rationalist reproduction lingers about, envisioning, perhaps, Derrida, in so much of Nietzsche's work: *Twilight of the Idols*, trans. R.J. Hollingdale, (Baltimore, 1968); *Human, All Too Human* and *The Wanderer and His Shadow*, trans. R.J. Hollingdale, (New York, 1986); *Thus Spoke Zarathustra*, trans. Walter Kaufmann, (New York, 1978); and so on. It is in the interplay of light and dark that meaning takes form; in the flux of this borderland, endless reiteration reigns. Fundamental to my present excursion is a suspicion concerning first principles. A multilayered question of persistent interest to me has been an apparently more open, inquisitive analog of the self-precluding proscription, "never say never"—namely, "why ask why?" This second order question might almost seem to invite mocking extension, successive questionings of the question itself, or it may even seem self-incriminating jest. However, it might also read as a profound metaphorical inquiry into the purpose of life (and knowledge) itself. A third order

reconfiguration of the bodies in which pathology is localized. Radical in a

rendition of the same nature—"why ask why ask why?—oddly enough, clarifies the possibilities, for, as a potential variation of its second order analog, it reveals the plight of aspiring to ordinary knowledge: the first order referent "why" in the second order question is stripped, in this form, of its object—it is either the universal "why", or the specific, elided of its less significant object. "Why ask why?" With this juxtaposition of similitude, this transduction of the scientific into the philosophical, I locate the intersection of the ethical and epistemic axes of knowledge production. And here I will linger.

⁴Why "I"? Surely, it is not I alone who is in this midst, or awash in the light of the day. Again, an instance of a probably ineffectual effort at resistance, an abstention from falling back on the universalizing, appropriating, distancing-without-divorcing, and profoundly irresponsible first-person plural by which "the scientific community" regularly refers to itself. Is it ironic, then, in light of f.1, that I should in this manner shun a rhetorical form which would allow me to disperse the responsibility of subjectivity through a plurally reinforced (and rarefied) "we", as well as favor a passive voice? Perhaps, but even more than the unreliability of the subjective I/eye, I find the invocation (at least in this case) of a collective, and implicitly objective, ethos or experience misguided. Moreover, I am emboldened, reading Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity* (New York, 1990), to forswear and absolve my "I" in rapid juxtaposition, recognizing that "'I' deploy the grammar that governs the genre of the philosophical conclusion, but note that it is the grammar itself that deploys and enables this 'I,' even as the 'I' that insists itself here repeats, redeploys, and—as the critics will determine—contests the philosophical grammar by which it is both enabled and restricted." (p. 146.)

different sense than the transformations to which Michel Foucault devotes his attention in *The Birth of the Clinic*, the shifting beneath my feet is not so much from one mode of medical perception to another (i.e., from a paradigm of classificatory spatialization to one based on the visual)⁵, as it is a manipulation of various "invisible"⁶ processes into the convenient and prevailing visual economy of knowledge.

In the service of this systematized enframing, an explosive procession of imaging technologies have emerged and suffused the worlds of scientific and clinical medicine, generating creative and elaborate methods of seeing both the body and mechanisms of disease. Among such innovations are the imaging technologies of endoscopy, which illuminates the internal spaces of living bodies for observation and intervention, and those which elucidate and instantiate *in vivo* structures and dynamics, as exemplified by radiography, thermography,

⁵Foucault, Michel, *The Birth of the Clinic: An Archaeology of Medical Perception*, trans. A.M. Sheridan Smith (New York, 1973). Indeed, the visual spatialization on which Western medicine came to rely through the inauguration chronicled in Foucault's early genealogy is more firmly entrenched than ever. The transformation evolving about me is, as I qualify it, protracted—in *Medicine and the Reign of Technology* (Cambridge, 1978), Stanley J. Reiser quotes an example of its most nascent form which is coeval with the period examined by Foucault: an 18th century physician writing of the stethoscope, "We anatomise by auscultation (if I may say so), while the patient is yet alive." (p. 30.)

⁶Processes which depend for their image rendering on the transduction of some other form of energy (forms almost always sensorily imperceptible to humans) into visible spectrum electromagnetic radiation (i.e., radiation which ranges from $4.0-7.9 \times 10^{14}$ Hz).

ultrasound, computerized axial tomography (CT), nuclear magnetic resonance imaging (MRI), positron emission tomography (PET), and various procedures which utilize exogenously administered contrast dyes, or radiolabelled metabolic substrates, tracers, and monoclonal antibodies. Others, such as electrocardiography (ECG) and electroencephalography (EEG), offer access to temporal processes via visual codification (which simultaneously instantiates and preserves continuity), if not anatomic superimposition. Still others are employed to alter the spatial scale of perception: namely, various forms of increasingly powerful microscopy, as well as molecular separation and concentration techniques.

With the proliferation of imaging technologies, many of the images of medical importance—both micro and macro—"no longer have any reference to the position of an observer in a 'real,' optically perceived world,"⁷ and require an empirical and theoretical trust in the visual representation of "invisible" phenomena. Genetic mapping and sequencing, for instance, presage a potentially massive unveiling of unmanifest pathology, as conditions like cystic fibrosis, formerly defined by their clinical signs and symptoms, have been localized

*the impulsion to be
what I am not
streams from this bewildering
discourse
of truth
and resolution:*

⁷Jonathan Crary, *Techniques of the Observer: On Vision and Modernity in the Nineteenth Century* (Cambridge, 1990), p. 2. Indeed, would it be accurate, even, to refer to a visual imitation rendered through the transduction into visible spectrum light of energy induced in, generated by, or directed through an object as 'mimesis'?

to specific chromosomal loci.⁸ Thus, the body of the patient is grown amorphous, the unit which it constitutes is, with increasing appearance, indefinite.

Reconfiguring in this manner the bodies on which the medical gaze is cast evinces the epistemologically tenuous link between the bodies of medical knowledge *on* which and *with* which practitioners work. Because objectified bodies are shaped through that which locates and defines them, and because the corpus of medical knowledge evolves along the lines of fracture and through the windows which open (whether by chance or most naturally) in the objectified body⁹, the dialectic of application and derivation which cycles among the bodies of medical knowledge tends to an increasing fragmentation within the latter. Consequently, though physicians in all areas ply their trade on the geography of bodies, the surfaces they traverse and the maps they employ continue to diverge.

Quite often, as I struggle to imprint on my mind these assorted topographies, I reflect on my fascination with the nexus of seeing and knowing in medicine and ask what I find so unsettling. At one level—that on which I recognize an aesthetic affinity for the almost surreal renderings—I resent that my eye is not so keen as those of the mammoth imaging apparatuses. More

⁸CR Scriver, et al., ed., *The Metabolic Basis of Inherited Diseases* (New York, 1989), is the standard reference work and source of information about most hereditary disorders.

⁹This is an idea neither borrowed from or inspired by Foucault's *The Order of Things: An Archaeology of the Human Sciences*, (New York, 1970), but one which recalls his expansive exploration of the representational ordering of knowledge in a provocative text, which, without needing to say so explicitly, effectively serves to replace the modern observer into the very center of the observational would-be-object.

fundamentally, though, I am intensely conscious of the fact that "an observer is . . . one who . . . is embedded in a system of limitations,"¹⁰ and that the conventions inaugurated with the digression of the visual field from the "visible" are increasingly articulated without the benefit of a readily recognizable horizon. One of the paradoxes of progress, of staggering technological insight, lies in the effacement of any sort of general frame of reference—ethical, metaphysical, or epistemic.

The nostalgia of such brooding notwithstanding, I am aware that, to an

*the biological
imaginary
trumpets an order
inherent—*

impressive extent, the panoply of imaging technologies that have come to subserve the medical enterprise sharpen the clinical picture of disease. However, so entrenched in society is the veracity of vision, so persuasive is the

metaphorical equation of light and truth,¹¹ that the apparent clarity of medical imaging itself may ultimately prove obfuscating and deceptive, as it has since the very inception of radiography.¹² Indeed, it is common for advances in diagnostic

¹⁰Crary, p. 6.

¹¹See Hans Blumenberg, "Light as a Metaphor for Truth: At the Preliminary Stage of Philosophical Concept Formation," trans. Joel Anderson, in David Michael Levin, ed., *Modernity and the Hegemony of Vision* (Berkeley, 1993), pp. 30-62, for a delightful introduction.

¹²In their historical analysis of the moralization of 19th and early 20th century scientific image making, Lorraine Daston and Peter Galison, "The Image of Objectivity," *Representations* 40 (Fall 1992), include a look at dilemmas concerning the reliability of radiographic representation. In a fin de siècle conflation of science, the law, and the question of truth that would not seem out

imaging to confuse physicians' "perceptions of the natural history of [a] disease and its response to medical intervention," with one (among many) result being that patients are "now more likely to be given diagnoses of . . . gallstones, herniated disks, meniscal tears, deep venous thrombosis, and pulmonary embolism," coronary artery disease, and a number of cancers, most notably breast, lung, prostate, and cervical.¹³

Rather than an inclination to scrutinize such prevalence of the more dire *when all order emergent* increased ability and conditions, the rising among them, especially, tends to be misconstrued as indicating an elevated incidence of their occurrence.¹⁴ Often, the ruse is compounded, as the representational facility and

of place today, X-rays were at once *seen*, as "preempt[ing] and displac[ing] all other forms of knowledge," and *seen through*: "the ray has many tricks, and we cannot always believe what we see, or rather fail to see." (pp. 110-111.)

¹³William C. Black and H. Gilbert Welch, "Advances in Diagnostic Imaging and Overestimations of Disease Prevalence and the Benefits of Therapy," *The New England Journal of Medicine* 328 (1993), pp. 1239, 1241, also references studies in which each of the adduced clinical conditions was investigated.

¹⁴One example of such complicitous facilitation of misperception is that of intensified visual screening programs—mammography, for example—engendering a thoroughly confused popular conception of risk. The issue of the visual and the mathematical, I believe, is integral to the larger themes of this essay: Even more so than the visual, perhaps, the most consistent substance of scientific knowledge and the universal standard of measurement and normativity, (as well as the language of most energy transducing imaging technology, and a key to appreciating the complexity of physiologic vision itself) is the numeric, or

mathematical. (See Thomas S. Kuhn, "The Function of Measurement in Modern Physical Science," in *The Essential Tension: Selected Studies in Scientific Tradition and Change* (Chicago, 1979); and Ian Hacking, *Representing and Intervening: Introductory Topics in the Philosophy of Natural Science* (Cambridge, 1983)). It is not surprising, then, that the visual and the mathematical should so often work in concert to justify, enforce, and enhance the epistemic regime they mutually command. As Martin Heidegger points out in "The Age of the World Picture," in *The Question Concerning Technology and Other Essays*, trans. William Lovitt (New York, 1977), "Only because numbers represent, as it were, the most striking of always-already-knowns and thus offer the most familiar instance of the mathematical is 'mathematical' promptly reserved as a name for the numerical. In no way, however, is the essence of the mathematical defined by numberness." (p. 119.) Indeed, that which is visually apprehensible—"no longer . . . that which presences," but that which is "set over against," objectified in its representation—wields an equivalent mathematical authority of being. (pp. 118-119, 149-150.) For, among the perceptual modalities, vision alone is capable of neutralizing the ephemerality of time, of compressing it into space, imparting to it a dimensional malleability which is conducive to the representation of nearly all forms of measurement. While Heidegger does not discuss the mathematicity of numerical mathematics itself, such a theme is of importance to the present essay. Ian Hacking has written much about "biopower and the avalanche of numbers" in such works as, *The Emergence of Probability: A Philosophical Study of Early Ideas about Probability, Induction and Statistical Inference* (London, 1975); "Biopower and the Avalanche of Printed Numbers," *Humanities in Society* 5 (1982), pp. 279-295; and *The Taming of Chance* (Cambridge, 1990). More fundamentally: though a variation

clarity of many of today's imaging technologies, perhaps as much as the value of their revelation, informs their application. For they are capable of "display[ing] anatomic derangements with such fidelity as to give clinicians the idea that they must follow where the images point to truth,"¹⁵ in effect "promot[ing] a cycle of increasing intervention that confers little or no benefit."¹⁶

on the recent spate of colloquialized and popularly marketed books by scientists, John D. Barrow, *Pi in the Sky: Counting, Thinking, and Being* (Boston, 1992), makes for an interesting look into the history and philosophy of mathematics.) For the most part, numbers do an adequate job of supporting the efforts of scientific and clinical medicine. However, in the context of a statistical mathematics wielded in ignorance, or simply ignored, the zeal of vision can readily expand into a creative envisioning, eventually begetting the imputation of a causal nexus, and consequent effect status, to "innocent" states. Though an awareness of the problem is creeping into many fields, the accessibility of statistical analysis via the routinization of statistical computer software is increasingly placing the power of the p value in the hands of those who have little or no understanding of the foundations of that which they use to "prove" what they claim. This is only the most obvious and practically remediable infraction.

¹⁵Howard M. Spiro, "Images and Realities," *Scientific American Science and Medicine* 1 (May/June 1994), p. 7.

¹⁶Black and Welch, p. 1237. One such terrain, albeit contested, is that of coronary angiography. Thomas B. Graboys, et al., "Results of a Second-opinion Trial Among Patients Recommended for Coronary Angiography," *Journal of the American Medical Association* 268 (1992), p. 2537, propose that, "Once coronary angiography is undertaken, the course is largely set," regardless of symptoms, and that "its sole intent is to determine whether coronary vascular

In this atmosphere of reductionism, fragmentation, and overextension, the steady inscription of diagnostic imaging applications as standards of prevention and care heralds a disorienting disarticulation of disease and dis-ease. While such phenomena as the detection of genetic "abnormalities" in asymptomatic individuals may allow for preemptive or otherwise significant clinical intervention, they also exemplify a visually mediated objectification of subjects along various and flexible contours. Thus, the value of diagnostic imaging techniques (especially, illumination that allows for early, sometimes critical treatment) must be weighed against their promise to set in motion a vast

*is constructed along
lines of selectivity
fragmentary chance
and heuristic—*

machinery of "making up people."¹⁷

In 1962, for example, Henry Kempe, a pediatrician studying a clinical condition heretofore known as

infantile cortical hyperostosis—signified by the coincidence in infants suffering from sub- or epidural cranial hematoma of inexplicable opacities (indicating healing or healed fractures) in X-ray images of their arms or legs—posited a

lesions are deserving of bypass or are amenable to angioplasty." Spiro, as well, recognizes that "With their scopes and scans, physicians can find the anatomical seat of most complaints. Abnormalities so uncovered, alas, may not explain the patient's complaints, nor will the correction relieve the existential pain in their origin." (p. 6.)

¹⁷See Ian Hacking, "Making up People," in Thomas Heller et al. ed.

Reconstructing Individualism: Autonomy, Individuality, and the Self in Western Thought (Stanford, 1986), pp. 222-36.

phenomenon he termed "the battered child syndrome."¹⁸ Though, clearly, Kempe's "discovery" of "the battered-child syndrome" via the insight of X-rays led to a significantly bolstered protection of children from their parents or ostensible guardians, it also marked a major step in the ever-increasingly assiduous (and often pathologizing) policing of how parents parent.¹⁹

¹⁸C. Henry Kempe et al., "The Battered-Child Syndrome," *JAMA* 181 (July-Sept. 1962), pp. 17-24.

¹⁹Ian Hacking, "The Making and Molding of Child Abuse," *Critical Inquiry* 17 (Winter 1991): pp. 253-288, examines this particular issue in depth. Without probing the genesis and evolution of "child abuse" as a named, and hence created—for, as with Michel Foucault's "sexuality" (see *The History of Sexuality Volume 1: An Introduction*, trans. Robert Hurley (New York, 1978) there is no question that the rough core components of what has by now become indelibly inscribed into the social tablet as "child abuse" have perfused human parent-child relationships for many more than the 31 years since the "battered child syndrome" was postulated—phenomenon, I should note that the mobilization of forces (particularly medical) witnessed in the campaign against violence inflicted on children is impressive. But it was only after the visual illumination—at once a discovery and verification—of "child abuse" that normative childhood development indicators were marshaled into the policing of families. I do not deny the value of rigorously assessing child health and safety, even when normative standards are marshaled into the monitoring, but I cannot ignore my impression that state-compelled physician intervention is often a charade of sorts. When its articulations double as such glaring disclosure of social sanctioning of action on the basis of the inordinate power of a normative, and delusionally self-styled objective, science. In his essay on the topic, Hacking

asks, "And yet what have we got for more people and more time but more cases of child abuse?" (p. 258.) Eternal return.

Physicians, ever more frequently, are being enlisted as the eyes of the state. There has "long" been a legal requirement to report suspected child abuse, but two recently enacted legal stipulations have extended the mandatory regulatory purview of the practicing physician to cover both suspected illegal existence in the United States ("Proposition 187" says it all) and suspected domestic violence (amendments to California State Penal Code provisions, introduced in April 1993 as Assembly Bill No. 1652, and enacted in October 1993, require any "health practitioner employed in a health facility or clinic, or physician's office, . . . who has knowledge of or observes a patient who he or she knows or reasonably suspects has suffered . . . from any wound or physical injury inflicted as described [in existing law or] as a result of assaultive or abusive conduct, to report to a law enforcement agency."

Similar to signs of child abuse, often ensconced in the depths of the body and soul, the signs of domestic violence are rarely seen in the medical environment when we rely on the openly visible: only the bruises which sometimes shine through feeble efforts to disguise them, or the penetrating gaze of an X-ray tube, betray its wish to remain hidden, signaling its presence. Lurking behind, in the sacrosanct confines of the "parents' bedroom", that would-be-axis of sexual normativity, (See, especially, Foucault, *The History of Sexuality Volume 1: An Introduction* (New York, 1978)) its existence must otherwise be drawn out into discourse to be affirmed. For only when abuse calls attention to its presence is it defined as such; only when it is discovered, uncovered, can a pronouncement of its deviation from the norm be issued.

Though Kempe's 1962 revelations may have been "serendipitous", they were not out of place in the culture of American medicine. For a concerted machinery of prophylactic X-ray screening had been in place, peering into the bodies of the public, for quite some time by then. In an essay entitled, "Women, X-rays, and the Public Culture of Prophylactic Imaging," Lisa

Cartwright examines the visual ordering of bodies effected in the mid-twentieth

throughout all
a tarry
with the negative
reminds my restraint
—

By legal decree (in California and many other states), the role of the physician-healer in the interdiction of violent domestic situations is one of discovery, of bringing to light the hidden. Failing to inquire, a tacit encouragement of silence, is to sanction the potency and hegemony of violence, and to break the law. Thus distilled into law, the field of domestic power is drained of its complexity, with little respect granted to the fluidity of its expressions, which are is significantly more multifarious than standard psychosocial models (Babcock, Julia C., et al. "Power and Violence: The Relation Between Communication Patterns, Power Discrepancies, and Domestic Violence," *Journal of Consulting and Clinical Psychology* 61(1993), pp. 40-50.) would suggest: wielded by an abuser, it can dominate, dement, and destroy; in counterpoint, in the service of compassion, it can be employed to coax its nefarious hidden obverse out into the space of the visible, inducing it to speak and silencing it at once, casting off the domination, dementia, and destruction, while invigorating its other, its former object.

century through the surveillant vehicle of prophylactic imaging.²⁰ Moving from the deployment of X-ray screening campaigns against tuberculosis, which constituted a "sexualized spectacle" of "reencoding the private body as a public space that might be traversed by anyone," to the historical development of breast imaging technology, as distinguished by the tendentious reticence displayed among even active researchers, she sets out "to historicize the regard of bodies within the discourse of radiography."²¹

"Perhaps the greatest irony," she finds, "is that, while ultrasound was first researched for fetal imaging after . . . breast studies in the late fifties, by the eighties fetal imaging had become . . . the definitive use of the technique, while ultrasound mammography remained an experimental technique."²² Indeed, standard methods of imaging the fetus *in utero* are more sophisticated and illuminating than those employed to screen for breast cancer. Nevertheless, the practice of prophylactically imaging both the fetus and the breast, only recently swirling on the periphery of the window of medical knowledge and practice, have come to reside at its very center.

²⁰Lisa Cartwright, "Women, X-rays, and the Public Culture of Prophylactic Imaging," *Camera Obscura* 29 (May 1992), pp. 19-54, was published in the second of two *Camera Obscura* issues devoted to the topic of imaging technologies and inscribing science.

²¹Cartwright, pp. 29-30, 32.

²²Cartwright, p. 45. We can learn a bit about the iniquity of scholarly critiques in such positions of ignorance. There is little irony in her example, and the disparity of applications in ultrasound development correlate directly and strongly with the tissue medium(s) to be imaged and traversed. The breast, largely adipose tissue, is not at all well-suited for ultrasonic inspection.

"Since the spectacle's job is to cause a world that is no longer directly perceptible to be *seen* via different specialized mediations,"²³ nearly all forms of medical imaging, and certainly the visualization of such gendered forms/environments as the fetus *in utero* and the female breast, qualify as spectacular, not only to the physician and imaging technician, but to the imaged object and the general public as well. Infused with the similarly spectacular "avalanche of printed numbers" unleashed in the service of a normative medical science, imaging is mobilized in a futile bid to ameliorate the risk of uncertainty. It is thus that specular subjects come to demand their own surveillant objectification.

*a geometry
of vacuous arcs
filling out
in futility*

A paper exploring the complicitous obfuscation by imaging and statistics of any cognizable truth about breast cancer might spring smoothly from the present effort. However, the domain which holds the greatest interest for me at this point is that of fetal imaging and treatment.²⁴ Hacking suggests that "we

²³Guy Debord, *The Society of the Spectacle* (New York, 1990), sec. 18. How critical is Debord's "no longer", and does it render my position untenable?

²⁴Despite an abundance of studies debunking the myth of scientific objectivity (for only a few of the many critiques, see Thomas Kuhn, *The Structure of Scientific Revolutions* (Chicago, 1970); Richard J. Bernstein, *Beyond Objectivism and Relativism: Science, Hermeneutics, and Praxis* (Philadelphia, 1988); Bruno Latour and Steve Woolgar, *Laboratory Life* (London, 1979); and Joseph Rouse, *Knowledge and Power* (Ithaca, 1987)), the notion of an isolated, pure science wields considerable ideological and heuristic power. In response to this

represent in order to intervene, and we intervene in the light of representations."²⁵ While fetal representation has become firmly integrated into the medical domain, interventions in light thereof are situated much less firmly on the periphery of the window of knowledge and practice. In fact, in almost all dimensions of this politically charged (perhaps even more so than breast cancer issues) focus, I am coming of age on the cusp of the fetal frontier. And it is here, perhaps most poignantly, that I am able to *observe* the evolving constitution of the body and its pathologies, through a discourse of imagery, along epistemic and ethical axes which cannot but intersect.

Eventually, I will bring my gaze to rest on the specific interventional modality of fetal surgery. In order to appreciate the issues engendered in the developing project of *in utero* intervention, however, it seems worthwhile to

*the immanence of difference
in awareness:*

transit into the clinic by way of two starkly illuminating moments of fetal representation that have found their

prevailing lack of scientific self-reflection, perhaps, I believe that it is imperative to approach any project with an eye turned toward the questions of purpose, of meaning, and of context. Thus it is that I am inclined to specify here the genesis of my desire to explore the intersection of imaging, ethics, and expectation in the visionary moment of fetal surgery as a function of my medical student's impulsion to explore the world of pediatric surgery, which, itself, is related to my own personal history of a neonatally diagnosed congenital anomaly.

²⁵Hacking, *Representing and Intervening*, p. 31.

expression, surprisingly or not, at the level of the popular media, and through the relatively non-exclusive imaging technique of photography.²⁶

The cover of the April 30, 1965 issue of *Life* magazine featured "An unprecedented photographic feat in color . . . A living 18-week-old fetus shown inside its amniotic sac."²⁷ Twenty five years later, the August 1990 issue of *Life*

magazine presented "The first pictures ever of how life begins," again with its cover adorned by a photographed fetus—only a

circles of meaning
that will not
close

much earlier (seven-week-old) and less obviously anthropoid form—floating in its amniotic sac.²⁸ The two editions, so similar in surface appearance, yet so different, separated by a quarter of a century and a considerable degree of social change, beg comparative study. And, indeed, there are at least two feminist critiques, of which I am aware, that take on the task.²⁹

²⁶Tangential to the present discussion most notably at the point of the power conveyed by photography in medicine, Daniel M. Fox and Christopher Lawrence, *Photographing Medicine: Images and Power in Britain and America since 1840* (New York, 1988), looks at the way "orthodox medicine has used photography to represent itself" (p. 5), fleshing out the more focused expression of medical power transmitted through images of clinical and experimental objects of investigation.

²⁷*Life* (April 30, 1965).

²⁸*Life* (August 1990). The photographer of the images appearing in both issues was Lennart Nilsson.

²⁹Barbara Duden, *Disembodying Women: Changing Perspectives of Women and the Unborn*, trans. Lee Hoinacki (Cambridge, 1993); and Carol Stable, "Shooting

Sharing a concern with how the private experience of pregnancy, once the exclusive domain of women, has become a public experience interpreted and controlled by medical practitioners, largely through the use of imaging technology, Carol Stabile and Barbara Duden separately examine the shift in the visual field that takes place between the 1965 *Life* issue and the 1990. While Carol Stabile problematizes the "unprecedented" erasure of the pregnant woman—the "mother" in 1965—in 1990 fetal imaging as crucial to the representation of fetal autonomy, Barbara Duden examines the transformation of seeing between 1965 and 1990 that imparts to the female peritoneum a transparency which allows for the ideological vivification of the unborn. The two works are similar in many respects, such as their ultimate concern with the backgrounding of the woman, but their respective angles on the visual culture of medicine and science diverge quite noticeably.

The analytic emphasis of Stabile's piece is placed on the representative aspects of the discourse (as contrasted with the bilaterally visual), as she focuses on what she seems to feel is a near conspiracy of scientific and political collusion. Both narratives (those of the 1965 and 1990 issues of *Life*), she asserts, "invoke visual technologies in the interests of shifting political formations," and both make claims to an originary status in order to "secure authority in the debates about the ontological status of the fetus."³⁰ Because "questions about the status of the embryo/fetus are not ideologically urgent in the way they are after *Roe v. Wade*," she charges, there is no need to erase the mother from the fetal representations (the photographs and their supporting text) appearing in the

the Mother: Fetal Photography and the Politics of Disappearance," *Camera Obscura* 28 (January 1992), pp. 179-205.

³⁰Stabile, pp. 184, 188.

1965 *Life*. By 1990, however, there has been a "conservative restoration", which informs her interpretation of the more recent *Life* as essentially an ideological vehicle of the New Right, a popular elaboration of the medical community's determination—in the face of feminist and abortion rights gains—to reinscribe the maternal environment as an "inhospitable waste land."

I find it interesting that, despite her focus on popular media representations of the fetus, Stabile makes no effort to incorporate the public of readers to whom *Life* is marketed. Of course, as some element of the spectacle is implicit in just about any media representation, it would be hyperbole to suggest that she is unconcerned with the observing populace. But in thus eliding a discursive element that is fundamental to the simultaneously cohesive and fractious debate, namely, the pool of information consumers, she neglects to acknowledge the regenerative impetus of expectation on the surveillant medical machine.

*What trajectory
this that inveigles me,
lures me,
a denizen*

Barbara Duden, on the other hand, seems more appreciative of the covalence of surveillance and spectacle, identifying the transformation of sight between 1965 and 1990 as a shift from surveillant imaging to the primacy of the spectacle, and asking how ways of experiencing the body are mediated and transformed by ways of seeing (not simply representing) the body. Twenty-five years removed from the *Life* magazine of 1965, which "panders to the *libido vivendi*, the ravenous urge to extend one's sight, to see more, to see things larger or smaller than the eye can grasp—to see things which have previously been off limits," the 1990 feature is "mainly concerned with the depiction of things that lie beyond the eye's horizon,

which, to be 'seen', must be explained by some authority."³¹ "Increasingly," she continues, "the managed image has become the precondition for sight."³²

Duden, like Stabile, formulates her critique vis-à-vis a world-compressing instrument of popular media. But she interweaves her analysis of *Life* with historical and semi-ethnographic ruminations and accounts, all in an effort to more finely appreciate how some women today experience pregnancy,

*the immanence of difference
in awareness:*

compared with how their mothers—women of the past—might have. In the process, she

implicates medical science, but she is equally clear about the responsibilities of the public in the construction of scientific truths, the spectacular reification of datum into fact-of-life.³³

No doubt, the motive forces invigorating the progressive periphery of the window of medical knowledge and practice are manifold and complex.³⁴ In their

³¹Duden, pp. 15-16.

³²ibid., p. 17.

³³ Of course, the responsibilities are bidirectional. The source of most public knowledge of cutting-edge science is the popular media, and it is well-recognized that the popular grammar and syntax of science more closely approximate the journalistic stylism of their general public expression than the cautious precision of the scientific literature (Lawrence K. Altman, "Promises of Miracles: News Releases Go Where Journals Fear to Tread," *The New York Times* (Jan 10, 1995), p. B6. Thus, the exigencies of public relations and recognition are fundamental to the public dissemination of knowledge, contributing to the creation of images of possibility that far outstrip the realities of possibility.

comparative analyses of the two issues of *Life*, Stabile and Duden each dissect out elements integral to the equation—political agendas and the "sight-stimulating stare [that] is the viewer's contribution to the virtual reality the media create."³⁵ To restore to the dialectic of representation and intervention its proper complexity, as the inquiries discussed above help do, it is necessary also to recognize the completion of the hermeneutic circle according to which science—despite the occasional denigrations of philosophers, anthropologists, and other critics (including myself)—evolves. Thus, Hacking's proposition that "we represent in order to intervene, and we intervene in the light of representations" might be filled out with the admission that it is also in light of intervention that representation is solidified and reinitiated. At the fulcrum of the apparatus, the unit through which the contributing forces are channeled, is the physician-scientist.

Medical practitioners (in the clinic as well as the lab) construct realities,

<p><i>the burden,</i> <i>the power that</i> <i>I wear</i> <i>irrevocably</i> (?)</p>	<p><i>tropic to</i></p>
---	-------------------------

working on the bodies presented (and represented) as their objects (which are never passively accepted, but always interpreted, shaped, and contextualized). Moreover, as they

work on bodies, practitioners work on themselves (which are also not passively accepted, but interpreted, shaped, and contextualized), in a process of

³⁴A tremendous account of the "trial" and liberation of theoretical curiosity can be found in Hans Blumenberg, *The Legitimacy of the Modern Age*, trans. Robert M. Wallace (Cambridge, 1983).

³⁵Duden, p. 20.

Foucaultian "self-formation".³⁶ Though the "bioethical" posturing currently in vogue tends to conceive of an ethic of principles and problems, offering little explicit recognition of the ethical subject per se, "all moral action involves a relationship with the reality in which it is carried out, and a relationship with the self."³⁷ For the physician-scientist, this is a relationship with a reality defined in part by the limiting and limited context of the observer, which, of course, is infused with the exigencies of self-preservation and aggrandizement, and self-constituted in part as an observing subject.

In "The Image of Objectivity", Daston and Galison undertake to chronicle "the moralization of objectivity in the late nineteenth and early twentieth centuries as reflected in scientific image making," the ethical self-formation, as it were, of the observing and representing subject.³⁸ Emphasizing the multiplicitous nature of "objectivities" prior to the fusion of disparate concepts into the current blanket notion of objectivity as detachment, rectitude, and correctness, they trace the parallel evolution of imaging technologies and techniques, and moral dilemmas in which accuracy was weighed against moral probity.

Judging from the critiques of Duden and Stabile, and from the bulk of academic "bioethical" treatment of fetal surgery, it seems that nearly all morally forged links between visuality and knowing have been dissolved, the dialogue between them is one almost exclusively of technology and technique. And certainly, the rigorous self-regulation so common among the figures described by

³⁶See Michel Foucault, *The Use of Pleasure: The History of Sexuality Volume 2*, trans. Robert Hurley (New York, 1985)

³⁷Foucault, *The Use of Pleasure*, p. 28.

³⁸Daston and Galison, p. 81.

Daston and Galison is unlikely in this era to be generated by an explicit morality, even when such impetus is present. But, of course, medical morality has been transformed as well. The appropriation of ethical issues in medicine by the institution of "bioethics" has, in effect, and ironically, served to segregate (or at least to enhance the segregation of) morality from science. To be sure, "bioethics" effectively came into being because the knowledge produced and the practices constructed along the periphery of the window of episteme and praxis became less reliable, more suspect. It was, and is, intended to help contextualize medical decision making in the increasingly complicated setting of a "science" divorced from the experiential. Ironically, however, it has secured a particular mode of contextuality, one which not only accommodates the scientific pretense of objectivity, in its current blanket sense, but which implicitly sustains it.

Before elaborating on the bioethical treatment of fetal surgery, a brief introduction to the rationale behind this supersubspecialized domain is in order. In part, this course from one bioethics to another, of the principled for the common sense order it really is.

*even as
its escapist imagery
confronts me
binds me,*

introduction will follow a fundamental principle of as an executive revelation organization of bioethics

Fetal disease, loosely entertained, can refer either to a condition which compromises the fetus per se, or to a condition in the fetus which does not necessarily compromise the fetus but which does compromise the newborn.³⁹ In

³⁹A more basic problem, namely, that of whether disease must be manifest to qualify as disease, is something I discussed briefly earlier, but which I feel compelled to recall here, having posited the notion of fetal disease. By definition, a congenital anomaly is present at birth—this is what “congenital”

many cases, there may be a benefit to treating fetal disease. The fetal milieu and physiology differ considerably from those with which the neonate must cope, which can confer a variety of therapeutic advantages. The primary physiologic difference in the fetus is the existence of parallel circulations and non-pulmonary oxygenation, which requires no pulmonary function and allows a fairly wide latitude of compensation for cardiovascular dysfunction and convalescence. It has also come to be realized, largely through research in areas of fetal surgery, that wound healing in the fetus often proceeds without the formation of fibrous scar tissue, a fact which has also come to be seen as a potential advantage of fetal surgery, as scar formation can have both cosmetic and physiologic implications.⁴⁰ In addition, the most compelling argument for fetal surgery revolves around the likelihood that many of the most severe structural congenital diseases develop as secondary processes to more basic lesions of either an obstructive or defective nature.⁴¹ In such cases, correction (or even partial correction) of the primary

means. However, the demarcation of birth is of variable significance with respect to the ontogeny and the expression of disease. For example, a fetal arrhythmia detected before birth is considered a form of congenital heart disease. However, it is possible for an arrhythmia of an identical electrophysiologic substrate to manifest only postnatally. Such a case is generally not considered congenital.

⁴⁰N. Scott Adzick, Michael T. Longaker. *Fetal Wound Healing*. (New York, 1992).

⁴¹Michael R. Harrison et al., ed., *The Unborn Patient: Prenatal Diagnosis and Treatment* (Philadelphia, 1991); Hanley FL. "Fetal Cardiac Surgery," In: Karp RB, et al. (eds.). *Advances in Cardiac Surgery vol. 5*. (New York, 1994), pp. 47-74.

lesion may substantially alleviate the impetus for secondary pathophysiologic developments.⁴² Beneficence, if only theoretical, firmly established.

The conceptual reciprocal of beneficence, namely, non-maleficence, holds that the physician do no harm. Though there are risks attendant upon any surgery, maternal and fetal morbidity associated with clinical and experimental fetal surgery has proven to be minor. One of the major impediments to successful fetal surgery in humans has been the high incidence of premature labor secondary to the hysterotomy and uterine manipulation required for fetal access. The result has been frequent premature delivery, which not only poses different risks for the fetus and potentially mitigates the benefits that can accrue from fetal intervention, but has potential implications for the health of the woman as well. Issues of fetal surgery and safety are yet to be fully characterized, and will likely become better understood as research in all areas of this field continues. This said, it should be noted that there are critics who subscribe to more starkly hierarchical ethical orders in which they articulate a different take on the principle of non-maleficence, reframing the principle from one which regulates activity to one which compels it:

*somehow
well*

The primary ethical imperative of medicine is to do no harm and *to prevent harm* if at all possible. The harm *caused* to a future child by refusal of proven fetal therapy that carries a risk to the mother

⁴²It is important to acknowledge that there are many other physiologic differences in the fetus, some of which may actually detract from the value of fetal intervention, such as, for example, the relative inability of the fetus to mount a metabolic stress response. However, most such issues are not well worked out, so it is not clear how much of an impact they will have.

acceptable to a 'reasonable' pregnant woman' . . . cannot be morally absolved by appeal to the doctrine of autonomy.⁴³

Little dialogic insight can come from such contentions, which effectively impose on the pregnant woman a duty both to open herself to "proven fetal therapy" and, practically speaking, to subject herself to the surveillant gaze of the medical panopticon. (This blatant abrogation of thought, under cover of principled reasoning, in an already tenuously ordered system would be humorous if offered

its travails fail
to locate
and
thus is its freedom
not as free
as it might be

as deliberate irony, but, offered as principled reasoning, saps any authority in the speaker's argument. First of all, the subtle interjection of "*to prevent harm*" extends the purview of the non-maleficence principle. Secondly, reference to the notion of beneficence is conveniently absent, a lacking which facilitates the expansion of non-maleficence, a displacement of balanced order in favor of a single hegemonic principle). The weighing of non-maleficence, misconstrued though it may be in the present example, against autonomy is an overly simplistic, and all-too-common, attempt to shortcut the critical inquiry such complex scenarios demand.

Nevertheless, such opinions cannot be dismissed out of hand, for in many ways they reflect a potential trajectory of legal logic regarding this issue, and it may very well be in the courts that the most contentious issues regarding fetal surgery surface and have their fate unfold.

⁴³Albert R. Jonson, "The Ethics of Fetal Surgery," in George L. Annas, ed., *Genetics and the Law III* (New York, 1985), p. 365. (italics added)

As of 1987, court orders had been obtained for cesarean section in 11 states, and were approved in 86% of the 21 cases in which they were sought, usually within six hours.⁴⁴ In an editorial accompanying Kolder's report in the *New England Journal of Medicine*, George Annas, who seems to be one of the most thoughtful and sensible commentators on issues of medical-ethical and medical-legal concern, defended the importance of informed consent in maternal-fetal issues, because, in the absence of informed consent, he said, access to the fetus,

*in that of where I am
that of my isolation
there
and, perhaps,
of where I will never be able to be*

whether viable or not, can be gained only "by treating [the mother] as a fetal container, a nonperson without rights to bodily integrity."⁴⁵

In response to this article and editorial, a lawyer who is active in the field and who wrote the chapter on legal considerations in the most widely circulated text on fetal treatment, sent a letter to the editor suggesting that mothers should be held criminally or civilly liable after birth for behavior that seriously injures their offspring, since pregnant women have no moral right to injure children who would otherwise be born healthy.⁴⁶ (Does this sound familiar? Does it echo the sentiment expressed only two pages back?)

⁴⁴VE Colder, et al. "Court-ordered Obstetrical Interventions," *New England Journal of Medicine* 316 (1987), pp. 1192-6.

⁴⁵George J. Annas. "Protecting the Liberty of Pregnant Patients [letter]," *New England Journal of Medicine* 316 (1987), 1213-4.

⁴⁶John A. Robertson. "Court-ordered Obstetrical Interventions [letter]," *New England Journal of Medicine* 317 (1987), p. 1223.

This opinion, along with that quoted earlier, as limited and limiting as they may be, are not all that far-fetched, at least in the realm of public discourse. In the legal domain, there is something known as a tort-for-wrongful-life suit, in which suit is filed by parents or offspring on the basis of the contention that either a third party, such as a physician or genetic analysis lab, or the parents of the offspring, are legally responsible to make restitution for an "injury" to the

*Would that
this open wound
in humanity
mend
and cordon off
the misery*

child that could have only been avoided by the child not having come into existence. Preceding the concept of tort-for-wrongful-life was that of wrongful birth.

In both *Gleitman v. Cosgrove* and *Stewart v. Long Island College Hospital*, the plaintiff was a mother who sought recovery on the basis that she was not informed, after contracting rubella during pregnancy, that many physicians considered abortion a proper option in such a situation.⁴⁷ The parents were awarded damages in both of these cases, but the children were not. Hence, these were cases of wrongful birth rather than wrongful life. More recently, in *Curlender v. Bio-Science Laboratories*, a California couple who gave birth to a child with Tay-Sachs disease sued the lab on the basis of incorrect transmission of information regarding their both being carriers of the gene.⁴⁸ The court awarded damages to both the parents and the child. In addition, the court raised the possibility that parents might be liable to children for proceeding with a pregnancy which they knew would lead to damaged offspring. Such parental

⁴⁷ *Gleitman v. Cosgrove*, 227 A2d 689 (NJ 1967); *Stewart v. Long Island College Hospital*, 296 NYS2d 41 (1968).

⁴⁸ *Curlender v. Bio-Science Laboratories*, 165 C 477 (Cal App 1980).

liability has since been rejected in California in *Turpin v. Sortini*, and has been precluded by the California legislature.⁴⁹

However, this is not a moot issue, and it may very well be re-inspired if fetal surgery becomes a widespread clinical reality. With respect to ethical issues surrounding fetal surgery, especially regarding the issue of maternal-fetal conflict, the

seek

following

may become a

*my will to heal bodies
singular
and collective*

decision whether to
therapeutic abortion
prenatal diagnosis
critical moment on

the decision tree. If the option for termination at the point of diagnosis is rejected, what becomes of the primacy of woman's choice (assuming, for the moment, that abortion remains a legal option)? Does this single rejection of the option of termination represent a commitment that irrevocably mediates freedom of choice? Does this decision shift the balance so as to more fully validate the significance of viability as a moral and/or legal watershed?⁵⁰ If proven fetal therapy is available, and a decision to forego abortion is made, will the possibility of rejecting fetal therapy even remain an option? That is, is there sufficient moral sustenance to say 'no' to therapeutic abortion and 'no' to proven fetal treatment?

Of course, these are complex questions, which require much consideration. I think it is important, here, to reflect upon the intersection of this realm of possibility and that advocated by Lindsay Allan, one of the most influential figures in the field of fetal echocardiography, and a strong advocate of using this technology as a means of extending informed opportunity for early second

⁴⁹*Turpin v. Sortini*, 643 P2d 954 (Cal 1982); Cal Civ Code §43.6.

50

transvaginal probe at 13-15 weeks has been reported,⁵³ but it is not until about 15-16 weeks that a transabdominal probe is effective.⁵⁴ All known forms of congenital heart disease have been detected by fetal echocardiography, though diagnostic accuracy is variable, and seems to depend on where the study was done and the specific type of lesion. In short, though plenty of uncharted terrain remains with respect to the diagnosis of fetal disease,⁵⁵ it does not seem that the *ability* to diagnose surgical congenital anomalies *in utero* will be the factor which limits the practical extension of fetal surgery.

What are the implications of this trend toward prenatal diagnosis? If fetal diagnosis is not made, therapeutic options are much as they were in the past,

*and the surface of my vision
my looking into myself*

insofar as diagnosis and the decisions it necessitates still come only postnatally, if at all. However, if fetal diagnosis is made, though the options that are available with postnatal diagnosis remain, the possibilities are potentially increased by at least three. Namely, this information can serve as the basis for therapeutic

⁵³Reuwan Achiron, et al. "Transvaginal Echocardiographic Examination of the Fetal Heart Between 13 and 15 Weeks' Gestation in a Low-Risk Population," *Journal of Ultrasound Medicine* 13 (1994), pp. 783-9.

⁵⁴GR DeVore, et al. "Fetal Echocardiography: The Prenatal diagnosis of a Ventricular Septal Defect in a 14-Week Fetus With Pulmonary Artery Hypoplasia," *Obstetrics and Gynecology* 69 (1987), pp. 494-7.

⁵⁵Much of my specific discussion will focus on congenital heart disease, for it is this domain with which I am most comfortable, but I will attempt not to dangle generalizations that apply to congenital heart disease but not to most other forms of congenital disease potentially treatable *in utero*.

trimester abortion. Fetal echocardiography, the very same imaging modality that Allan trumpets as a medium to help women make informed choices about abortion, is the foundation for fetal surgery, which, in this scenario I have just outlined, has the potential to effectively regulate reproductive choice. Thus, the tension.

Codified in terms of the ethical precepts of beneficence, non-maleficence, autonomy, and justice (which, as a concept, is limited for the most part to questions of allocation), fetal imaging is rarely considered,⁵¹ though it is arguably the most critical element of any fetal surgery project. The ability to diagnose

might spring free

*from the portent
that guides it,*

structural/surgical congenital anomalies *in utero* is becoming more refined as technology is focused and the clinical and

academic impetus grows. Congenital heart disease has been diagnosed as early as 11 weeks gestational age (only a week or so after the completion of cardiac morphogenesis) with a transvaginal probe.⁵² Routine screening with a

⁵¹However, it was argued in one relatively early paper, John C. Fletcher, "The Fetus as Patient: Ethical Issues," *The Journal of the American Medical Association* 246 (1981), pp. 772-774, that a higher moral evaluation of the fetus would result from its visualization or treatment.

⁵²U. Gembruch, et al. "First-Trimester Diagnosis of Fetal Congenital Heart Disease by Transvaginal Two-Dimensional and Doppler Echocardiography," *Obstetrics and Gynecology* 75 (1990), pp. 496-8.

abortion or, depending on the diagnosis, fetal treatment. A further option, again depending on the anomaly, is prenatal formulation of a postnatal treatment plan, which may include maternal transport to a tertiary care center that has an experienced neonatal surgery team, where the baby can be delivered and managed promptly.

There have not been many studies looking at the value of this option. There is one 1990 paper from the Children's Hospital of Philadelphia, which reviewed their experience with 22 neonates given the diagnosis of critical left ventricular outflow tract obstruction *in utero*, who were then referred for delivery and

sealing me in the flux

surgery.⁵⁶ Five of the newborns died without surgery. Thirteen

of the 17 who underwent stage I surgery survived and were discharged, and three of the remaining 13 died within 16 months, following second or third operations. In an analysis of the 17 patients who underwent stage I palliation, the authors found that newborns diagnosed prenatally had a lower incidence of preoperative complications and made it to the operating room at a younger age (reflecting a more stable postnatal course) than patients with the same lesions who were diagnosed postnatally. One month survival was better in the prenatal diagnosis group, though not significantly so, and was still less than stellar. A similar study by Harrison et al., in which 83 fetuses diagnosed with congenital diaphragmatic hernia before 24 weeks' gestation were followed until death or two months of age, found that 58% of the fetuses followed died by the age of one

⁵⁶Anthony C. Chang, et al. "Diagnosis, Transport, and Outcome in Fetuses With Left Ventricular Outflow Tract Obstruction," *Journal of Thoracic and Cardiovascular Surgery* 102 (1991), pp. 841-8.

month, with significant mortality *in utero* and immediately after birth.⁵⁷ The understanding of disease transformed, the "hidden mortality" revealed.⁵⁸

Lindsay Allan has published extensively on the subject of prenatal diagnosis of congenital heart disease and has found that, in her experience of 1,006 cases of congenital heart disease diagnosed *in utero* since 1980 at her high risk clinic in the UK, 55% of women decided on the basis of this knowledge to terminate the pregnancy.⁵⁹ Along with this, there was a documented drop in the prevalence of hypoplastic left heart syndrome in live births in her catchment area. In a separate study of neonates/infants presenting with congenital heart disease at her institution, published with Cullen as the first author, Allan and her group determined that 149 of 400 cases of congenital heart disease (283 of which were severe lesions) would have been detectable *in utero* on a screening four

⁵⁷Michael R. Harrison, et al. "A Prospective Study of the Outcome for Fetuses With Diaphragmatic Hernia," *The Journal of the American Medical Association* 271 (1994), pp. 382-4.

⁵⁸As the eye, the organ of seeing—in common but likely not conserved among the many eyed species—is an object of interest to evolutionary biologists and geneticists, so is the ever-expanding clinical eye a motor for evolution: the former "natural history" of many a disease (breast cancer, congenital heart disease, diaphragmatic hernia) has all but ceased to exist, as clinical insight has lifted one horizon (that of the unseen) and foreclosed another (that of untouched progression).

⁵⁹Lindsay D. Allan, et al. "Prospective Diagnosis of 1,006 Consecutive Cases of Congenital Heart Disease in the Fetus," *Journal of the American College of Cardiology* 23 (1994), pp. 1452-8.

chamber view at routine obstetric ultrasound.⁶⁰ Only eight were actually detected, and these were all found beyond 30 weeks gestation. Fifty-two percent of mothers, and 70% of those whose children had severe lesions, volunteered their preference for termination if the diagnosis had been made *in utero*. Allan recommends screening with a four chamber view, at between 18-20 weeks gestation, during routine obstetric ultrasound. The potential impact of widespread screening is clearly profound.⁶¹

The ethical principle of most practical import with respect to fetal surgery might be the principle of justice, which is a concept that has only recently come to be accepted as one of the cardinal principles of bioethics. In general, "justice" in this context refers to the allocation of resources, which becomes more and more of an issue as technology and diagnostic capabilities become more highly refined and health care costs increase at the rate they have been for the past couple of decades. The background of any research or clinical venture into the realm of fetal surgery should be the objective of reducing the incidence of congenital disease, extending and improving the lives of those in whom congenital disease does develop, and improving the overall health of society. Thus, it is important to view fetal surgery as part of a larger project. For

⁶⁰Seamus Cullen, et al. "Potential Impact of Population Screening for Prenatal Diagnosis of Congenital Heart Disease," *Archives of Diseases in Childhood* 67 (1992), pp. 775-8.

⁶¹It should be noted that this work was done in the UK, where later abortion is available and where a national health care system is in place and first and second trimester prenatal care, presumably, is more consistently obtained than it is in many areas of the US.

example, fetal diagnostic capabilities should be appreciated for all that they offer in addition to enabling *in utero* repair of congenital anomalies. What other benefits to individuals and society can accrue from a more extensive and intensive fetal screening program? Only a fraction of the congenital anomalies that can occur are likely to be amenable to *in utero* repair. Thus, if it can be shown that outcomes of neonatal surgery are better in infants who were diagnosed *in utero* than those who were not, it would be of benefit to screen for congenital disease regardless; however, as the studies by Chang et al. and Harrison et al., referenced earlier, demonstrate, it will be no simple matter to determine the postnatal impact of prenatal diagnosis. Moreover, if ever fetal surgery is to become as successful as it might be, it is imperative that access to care, including prenatal care, is improved for all people. If a large portion of the population in which fetal disease is present is not receiving prenatal care, fetal surgery is of no good to them. The impact predicted by Allen assumes and requires that early prenatal screening is widely available. Thus, it will be politically advantageous for fetal surgeons and researchers to support health care and public policy plans that improve access to care on a large scale. However, advocacy for extension of fetal screening, as a demonstration of social responsibility, will have to be balanced by a political awareness of the potential consequences of fetal surgery in general.

*from the portraiture
that envelops it*

Several pages back, I hinted at the possibility that a realized project of fetal surgery might valorize the ever-shifting precipice of viability. Chervenak, discussing the notion of the fetus-as-patient, hinges a critical aspect of his argument on the notion of viability, noting that the viability of a fetus is dependent on biologic and technologic factors that are not a function of a pregnant woman's autonomy,

so that "when a fetus is viable, the fetus is a patient."⁶² He goes on to contrast the viable fetus with the previable fetus, which can be linked to the child it can become only by the pregnant woman's autonomy, and be accorded the status of patient only by the woman's decision to so confer such status.⁶³ In elaboration, he also proposes that a patient is one who "can benefit from the application of the clinical skills of a physician," and that "someone is a patient when a physician has benefit-based ethical obligations to that person." But a patient need not possess an independent moral status. Is patienthood, then, defined by the capabilities and responsibilities of the physician?

Lest the reader of such passages leap from the word "patient" to the subjective person it may connote, I should caution that any ethical appeal to the moral edification or ideological vivification inspired by the imputation of patienthood to the fetus, insofar as it looks to broader moral concerns than the simple rule-based purview of bioethics, must likewise entertain the moral foundation of knowledge upon which this entire issue is based. Though the ideological inscription of "life" on the fetus may not seem far from the constitution of fetus-as-patient, the construction of a subject-of-sorts effected by the former, while arguably implicit in the objectifying reification of the latter, must be appreciated as a separate enterprise, one of terminal creative investiture

⁶²Frank A. Chervenak and Laurence B. McCullough. "Ethical Issues in Recommending and Offering Fetal Therapy," *Western Journal of Medicine* 159 (1993), pp. 396-9.

⁶³ Of course, the point of viability may be an appropriate measure in the current era (relatively speaking), given the significance accorded to this demarcation in *Roe v. Wade*.

rather than facilitation. But regardless of how I might haggle, this is where the ethical issues will shape up as contentions of high stakes.

Of women UCSF Fetal Program for regarding fetal	<i>where space revert</i> <i>and possibility to the absence they suggest</i>	presenting at the Treatment consultation surgery (not
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cardiac, which I've been focusing on but which is still just experimental), the great majority decline. Those who go through with fetal surgery, almost invariably, are women opposed to abortion. This may be a function of the relatively modest improvement in prognosis with many types of fetal surgery, and may not be an accurate reflection of what will happen if there comes a day when fetal surgery offers more than hope.

The conscientious approach most clinicians involved in fetal surgery at present seem to take is heartening, but, again, this is a reality that may be confined to their position on the cusp of the fetal frontier. The extension of scientific knowledge to the rhetoric of public discourse almost inevitably imbues the former with some degree of political urgency. Knowledge is political, even from the point of hypothesis, the point of conception—and it is malleable, it can be used in many ways. One of the ethical responsibilities most firmly incumbent upon those engaged in fetal surgery and research is forthright politicism. As I have suggested, they should be some of staunchest advocates for universal early prenatal care and should be on record regarding their political stance vis-à-vis the issue of reproductive choice.⁶⁴

⁶⁴Of course, there are bound to be both pro-choice and anti-abortion advocates among investigators involved in fetal surgery. Just as elsewhere in medicine, an individual practitioner's views on a particular issue, such as abortion, will

Moreover, they cannot defer to the "experts" when it comes to working out the ethics of fetal imaging and fetal surgery, which, in the most incisive of "bioethical" dialogues, is reduced to a potential conflict between fetal well-being and maternal autonomy.⁶⁵ By removing from the systematic principled analysis of "ethical" questions an actively self-reflective problematization of the very mythical notion of "maternal autonomy", for instance, the bioethical position, irrespective of its input, caters more than is morally propitious to the epistemic paradigms of the medical milieu it seeks to regulate. For instance, what insight can possibly come of projects that propose to ensure valid informed consent (to carry out fetal treatment) with precautions such as the appointment of "An impartial physician, involved in the fetal medicine team, to 'speak for' the fetus"?

Fetal surgery, still in its infancy as a clinical reality, is riding the crest of the reconfiguration of the bodies in which pathology is localized of which I am so

influence their actions, emphases, and political demeanor. While the laboratory or clinic may not be the place for political debate (or, as I believe, they may be), the ideological embellishments of knowledge produced can and do influence the facility with which this knowledge is appropriated and shaped. The concern I express is not one relating simply to the ethics of fetal surgery, but to all issues of bioethical consideration. A revised ethics, a prospective ethics of perspective, is a project I have in mind for bioethics, though it is not yet fully articulated and not presented beyond this brief reference in the present essay.

⁶⁵For a review, see John C. Fletcher and Albert R. Jonsen, "Ethical Considerations in Fetal Treatment," in Michael R. Harrison et al., ed., *The Unborn Patient: Prenatal Diagnosis and Treatment* (Philadelphia, 1991), pp. 14-18.

in awe. The possibility of surgical intervention into developmental processes gone awry in the unborn depends, seminally and fundamentally, on imaging the fetus. The frontier of fetal treatment, thus opened, is rippled with the legacy of all medical imaging, as well as the spectacular and political concerns explored by Duden and Stabile. However, it is subject to an institutionalized ethical framework which has come, increasingly, to focus on intervention much more heavily than the representational ground beneath it.⁶⁶ In general, I agree that

⁶⁶Though the institution of bioethics effectively came into being because the knowledge produced and the practices constructed along the periphery of the window of episteme and praxis became less reliable, more suspect—they could no longer be counted on to regulate themselves—it has yet to take up fundamental questions concerning the nature of medical knowledge. Likewise, it has yet to enter in earnest into the front-end fray over how knowledge and practice ought to be pursued and adopted. Whether it is insufficient for the task, unable to anticipate, or simply fashions itself an arbiter of the already-extant, it stands poised meekly behind the tide, its role restricted to one of palliation and patching holes, rather than beyond, where it might confront the advancing waves. For example, the questions most often adduced as ethical dilemmas—those such as whether to increase the rate of morphine infusion for a terminal cancer patient, a step which, in addition to easing their pain and helping them to relax, is likely to depress their respiratory center enough that they will stop breathing and die—are never so simple as their surface manifestation might suggest. Underlying most every unit of knowledge—including the detailed understanding of how and at what dosage morphine becomes effective, both as an analgesic and a respiratory depressant—is borne of animal (and sometimes human) experimentation. Thus, the decision of ultimate import in most perceived

intervention harbors a greater potential for begetting harm than does representation. Nevertheless, foreclosing from ethical consideration the epistemic foundations of medical science and practice contributes to the untethering loss of horizon effected with "habituation to the monopoly of visualization-on-command" posited by Duden as "strongly suggest[ing] that only those things that can in some way be visualized, recorded, and replayed at will are part of reality."⁶⁷

With the loss of horizon, of course, its necessary conceptual other, the center, is dispersed as well.

*wedged,
between the tensions of fluency and uncertainty*

clinical dilemmas hinges on the determination of antecedent ethical issues which are daily resolved, overlooked, or simply disregarded. I qualify this ethical framework as institutionalized, for I am concerned at present with the mainstream of medicine, that is, what the literature says. Though thus is the extent of my project in this essay, I hope, sometime soon, to explore the ethical perceptions and constructions of surgeons and researchers forging the fetal surgical frontier.

⁶⁷Duden, p. 17.