SPEEDING UP SLOW DEATHS: MEDICAL SOVEREIGNTY CIRCA 2005

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In this essay, I explore the relationship between temporality and power in the practice of medicine, or what I call medicine’s temporo-politics. I propose that we attempt to think the time of clinical medicine differently, not, or not only, as an emergency time concerned only with the present moment, but as a variable time that can be extended into the near or distant past and future via a variety of practices—clinical, scientific, discursive, and political. In order to explore the multiple temporalities of medicine, I take up the question of the time of medicine in relation to two events in the U.S. from 2005—the Terri Schiavo case and Hurricane Katrina and its aftermath. I consider both cases as “mediatized medical events,” that is, as events in which the practices of medicine received considerable media attention at a particular historical moment; or, we might say, as events that brought a convergence between media and medical practices. I locate that moment as “circa 2005” to remind us of something fairly obvious: that the events many of us witnessed in the media in

1 By highlighting the emergency time of medicine, I do not mean to suggest that medicine is not sometimes practiced in other temporalities. Recent attempts to better treat and care for chronic illnesses and intractable pain acknowledge the need to shift from an acute to a chronic temporal register in treating many conditions. For an early text that provides a better clinical method for dealing with chronic conditions, namely a sort of clinical ethnographic method, see Arthur Kleinman, The Illness Narratives: Suffering, Healing and the Human Condition (New York: Basic Books, 1988). Another example of the recognition of the multiple temporalities of illness can be seen in the increased number of longitudinal, as opposed to case-control, studies of particular diseases.

2 When I presented an earlier version of this paper at a seminar at Queen’s University Belfast on “Retheorising Women’s Health: Shifting Paradigms and the Biomedical Body” organized by Margrit Shildrick and Azrini Wahidin, one participant found my description of Hurricane Katrina and its aftermath as a “mediatized medical event” to be a bit of a stretch, arguing that Hurricane Katrina was about a lot of things, but not really about medicine. While I certainly agree that Hurricane Katrina is an event that cannot be encapsulated in any single phrase, and that its eventfulness cannot be characterized as solely, or even mainly, medical, nonetheless I do think we can, and indeed should, use the catastrophe of Hurricane Katrina as a lens through which we might view some of the practices of medicine, especially those that respond to crises. Keith Wailoo makes a somewhat similar point in his recent essay on dialysis patients after the storm, see Keith Wailoo, “A Slow, Toxic Decline: Dialysis Patients, Technological Failure,
2005 began long before that time, and did not end once the media coverage ended, but are ongoing in the present and into the future.\(^3\) I also want to think about how both the Schiavo case and Hurricane Katrina might be understood as catastrophes—as events that produced a subversion of the order or system of things, at the level of both individuals (in the case of Schiavo) and populations (in the case of Hurricane Katrina). Yet, what was subverted and reordered, and how? This isn’t entirely clear, even six years after the events and their prominent media coverage, and, thus, I want to think about the multiple ways power is exercised in times of subversion, reordering, and uncertainty, and after.

I juxtapose these two events because, placed side by side, they help make visible two stories of catastrophe, as well as the many difficulties of telling stories of catastrophe. In bringing together these seemingly divergent events, I hope to demonstrate the bioconvergent character of catastrophe, allowing me to draw connections that I hope will expand our bioethical imaginary beyond the reductive approaches that tend to dominate the practice of bioethics today.\(^4\) I also juxtapose them to signal a bioethical tension at the

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3. My understanding of what I am calling the “circa-ness” of these events owes much to Kim Fortun’s brilliant study of the catastrophic poisonous gas leak in Bhopal, India in 1984, *Advocacy After Bhopal: Environmentalism, Disaster, New Global Orders* (Chicago and London: University of Chicago Press, 2001). In its approach, *Advocacy After Bhopal* considers how the disaster in Bhopal in 1984 reverberates beyond that particular moment and place, into the past and future. Organizations like the Bhopal Group for Information and Action and the Bhopal Gas Affected Working Women’s Union, middle-class advocates, including Fortun herself, and also the text of *Advocacy After Bhopal* all struggle to respond to the disaster. That disaster is not over and done with once the gas has stopped leaking, but continues in small things like mutated genes and damaged bodies and in large things like ethnic and religious conflict and grassroots challenges to corporate malfeasance. We can only respond, Fortun believes, “[t]entatively. Reaching for something that can’t yet be named. Pursuing new linkages, as a way around available—and obsolete—idioms and social forms” (194).

4. The President’s Council on Bioethics, created by an Executive Order signed by President George W. Bush on November 28, 2001, and renewed every two years until the order was allowed to expire under President Obama on September 30, 2009, provides a useful institutional example of the hegemonic bioethical imaginary of recent years. The list of “Topics of Council Concern” and the transcripts and reports published on the Council’s website suggest that bioethicists are mainly preoccupied with questions concerning the proper use of medical technologies. Although there is material on “Health Care” and “Human Dignity,” the list is dominated by topics related to particular biotechnologies and their regulation.
heart of the neoliberal state’s response to catastrophe in general, what Foucault might have diagnosed as the difference between making live and letting die. In these two events, we glimpsed—if only fleetingly—the state’s operation of making live and letting die, and medicine’s central role in that operation. In the Schiavo case, we saw making live in action, as a demonstration of the expertise of doctors. What we did not see was the day-to-day care of someone in Schiavo’s condition—however we categorize it—since 1990, or what led to her catastrophic medical event in 1990. In the Katrina catastrophe, we saw countless images of weak, sick, and disabled people exposed to the elements, struggling simply to survive. We also saw—starkly, if again only fleetingly—the unequal distribution of health resources and the shocking inadequacy of care for our most vulnerable citizens.\(^5\) The usually slow deaths of neglect were speeded up and in this way came to our attention. Or, put differently: because of the mediatized medical event arising from a supposedly natural disaster, the endemic of vulnerable citizenship—or “bare life” in the Italian philosopher Giorgio Agamben’s terminology—became denaturalized and deprivatized for a brief time.

Through the convergence of these two cases, I want to problematize the relationship between what comes into view and what doesn’t, and between the act of seeing and temporality. What is the difference, for example, between something that is glimpsed and something that is seen over and over again, and what happens when both of these visuo-temporal modalities (glimpsing and seeing over and over) are operating at the same time? As I will show, the most visible after-effect in the U.S. of the mediatized medical event of Katrina has been an increased concern with disaster preparedness, which I argue is a sign of a re-assertion of medical sovereignty. Institutes for crises, disasters, and risk management have popped up everywhere, and while their stated mission is to help us better prepare for the next catastrophe, an unstated mission seems to be to help medicine and the state better prepare for the next mediatized medical event, and to become immune from liability and obligation in such events. Meanwhile the slow catastrophes—of inadequate healthcare, endemic poverty,


\(^5\) Wailoo emphasizes the seeming contradiction in the relationship between technology and vulnerability: “The failure of dialysis technology—like failed levees, canals, and pumps—revealed the weakness in a technologically reliant society” (“A Slow, Toxic Decline,” 36). If we think in terms of the convergence between technology, bodies, and media, we can begin to understand this relationship as not so much contradictory as pervasive under neo-liberal regimes.
and the limited distribution of fresh and affordable food—continue. How do we attend to them?\(^6\)

**Biopower and bioethics: Promoting a culture of life**

Visitors to the official U.S. government website\(^7\) in early 2008 would have discovered a fascinating document chronicling an impressive “Record of Achievement” of the George W. Bush Administration. Comprised of 19 short chapters, the Bush Administration’s “Record of Achievement” signaled its priorities in both its content and structure, beginning with chapters on security, then moving to chapters on economics, and finally covering other topics, including health, education, fighting crime, strengthening the judiciary, and protecting the environment.\(^8\) Towards the end of the document are three chapters—“A More Compassionate America,” “Protecting Children, Strengthening Families,” and “Promoting a Culture of Life”—that clearly set out the Bush Administration’s conservative ideology. I will focus briefly here on the goal of promoting a “culture of life” in order to introduce the Foucauldian concept of biopower as it was practiced by the Bush Administration circa 2005.

In a speech in 2003, President Bush articulated his administration’s “culture of life,” the enactment of which is interesting in both spatial and temporal terms. He asked that we “broaden our circle of moral concern” to include the interests of the unborn, and he emphasized the founding democratic principles of the United States as providing a guide for building a culture of life in the present and for the future. At the annual anti-abortion march in January 2005, President Bush presented an image of a future America, telling marchers

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\(^6\) This essay is part of a larger project that looks at what I see as two lacunae in medical education, thought, and practice: history and the politics of representation. The question the larger project asks is: How can we attend better to history and the politics of representation in medicine, and what benefit—clinical, methodological, and theoretical—might accrue from such attention? At the center of that larger project are the emergent health practices and institutions of the 1960s and 1970s, including the feminist critique of medicine that was a central plank in women’s liberation politics, along with the widespread development of community health clinics in communities of color. I explore the continuities and discontinuities between the health activism of this period and later AIDS activism in a work in progress entitled, *Underlying Conditions: A Prehistory of AIDS, 1960-1980.*


via telecast, “The America of our dreams, where every child is welcomed … in life and protected in law, may still be some ways away. But even from the far side of the river … we can see its glimmerings.” In that same speech, Bush also addressed his concern that scientific and medical technologies often advance more quickly than our ability to fully understand the ethical ramifications of such advances. Ethics moves at a slower, more deliberative pace than technology, Bush argued. Bush’s formulation of the concept of the culture of life was decidedly vague in January 2005, but by the end of that year, the contours of the concept and its practices would be more clearly mapped out for the American public. Indeed, from the far side of another river we did see its glimmerings, and it resembled, eerily, Foucault’s concept of biopower.

According to Foucault, biopower is comprised of the “numerous and diverse techniques for achieving the subjugation of bodies and the control of populations.” In his lectures entitled, “Society Must Be Defended”, Foucault describes the transformation in the nineteenth century from a right of sovereignty to “take life or let live” to a new state right to “make live and let die.” In this shift, which is facilitated by the emergence of new technologies and practices, like biostatistics, the state becomes concerned with monitoring and maintaining the health of individuals and populations, and medicine is a— if not the— key site for the practice of making live and letting die. At the same time, I think not coincidentally, medicine itself professionalizes at the end of the nineteenth century, and begins to become the powerful profession it is today. In Homo Sacer, Agamben develops Foucault’s concept of biopower, exploring further its relationship to sovereign power. Agamben corrects a frequent misreading of Foucault, which contends that sovereign power disappears with the emergence of biopower. What Agamben demonstrates is not the way one form of power displaces the other, but the “hidden point of intersection between the juridico-institutional and the biopolitical models of power,” and he makes a compelling argument that, “the production of a biopolitical body is the original activity of sovereign power.”

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be understood, then, as a bioconvergent form of power, not replacing an older form of power, but consolidating and transforming that power.\textsuperscript{13}

In order to analyze the workings of biopower, Agamben, like Foucault, takes medicine as an exemplary domain in and through which life and death become politicized. As is noted by many commentators on his work, in the final section of \textit{Homo Sacer}, Agamben discusses the concentration camp as the paradigmatic location for the exercise of biopower, and, bringing together Arendt’s thought with Foucault’s, he also identifies the refugee as a figure of bare life.\textsuperscript{14} What is less frequently mentioned is that in this section Agamben also discusses the phenomenon of “\textit{coma dépassé}” (a phrase he suggests might be rendered as “\textit{overcoma}”\textsuperscript{15}) as a new experience and event that redefines the threshold between life and death. For Agamben, the hospital room in which the neomort, overcomatose person, and the \textit{faux vivant} waver between life and death delimits a space of exception in which a purely bare life, entirely controlled by man and his technology, appears for the first time. And since it is precisely a question not of a natural life but of an extreme embodiment of \textit{homo sacer} (the comatose person has been defined as an intermediary being between man and an animal), what is at stake is, once again, the definition of a life that may be killed without the commission of homicide (and that is, like \textit{homo sacer}, “unsacrificeable,” in the sense that it obviously could not be put to death following a death sentence).\textsuperscript{16}

Agamben identifies new figures of bare life—the refugee and the overcomatose person—and new threshold spaces—the concentration camp and the hospital room in which a “brain dead” person is kept on a respirator to allow for organ transplantation—that emerge in the twentieth century. These figures and spaces will appear in the two cases circa 2005 that I discuss here. Whereas Foucault and Agamben frame their discussions of biopower mainly in spatial terms, I want to elaborate and extend their spatial analyses by focusing here on the temporal aspects of the exercise of biopower.

\textsuperscript{13} Thanks to Deborah Lynn Steinberg for this insight.
\textsuperscript{14} In his introduction, Agamben calls it a “curious fact” that Arendt and Foucault never seemed to take note of each other’s work. By reading them together, Agamben belatedly makes a connection between these two key twentieth-century thinkers on how power is enacted.
\textsuperscript{15} Agamben, 1998, 160.
\textsuperscript{16} Agamben, 1998, 165.
What I also want to think about with and through the two mediatized medical events circa 2005 is how in the cases of Terri Schiavo and Hurricane Katrina the usually invisible state practices of making live and letting die—“the hidden point of the intersection between the juridico-institutional and the biopolitical models of power”—came into view, if only fleetingly. In general, mediatization works to extend biopower and cover over sovereign power. But, in the images that circulated around these two events, the U.S. state in general and medicine in particular were exposed, even over-exposed, and the practices of diagnosis and treatment were deprivatized and denaturalized as they became subject to very public operations of interpretation. To put it simply: in the hallowed halls of the U.S. government and in the flooded streets of New Orleans, we saw medicine in action. Yet, for all we saw in 2005, we are still discovering much that was kept from view, never mind all that we are still not discovering, all that, as yet, remains out of view. How, then, do we keep open the space and time of this “as yet”? One way to do so, I think, is by bringing together two divergent cases that do not immediately seem to belong together, visually or conceptually, spatially or temporally. As a genealogical method, bioconvergence seeks to make linkages between and across disparate biomedical events and practices in order to provide denser analyses of very particular problems. In what follows, I hope to do a bioconvergent genealogy that moves outward from the particular temporal site of the year 2005, and from the particular spatial sites of an embodied condition—in the case of Terri Schiavo—and a particular socio-environmental condition—in the case of New Orleans after Katrina.

**Medicine in action 1: Making live and letting die**

There are many twists and turns to the Terri Schiavo case, and I cannot claim to do justice to the complexities of the case in this short essay. By focusing on some very specific events of 2005, I do not mean to reduce the long denouement of Schiavo’s life to a video clip and a speech on the U.S. Senate floor, although that reduction is also part of the story of Schiavo’s life. Rather, I hope to analyze these mediatized medical events to explore questions of temporality and medical sovereignty in a case that demonstrates both making live and letting die, and the essential relationship between the two in Foucault’s formulation.  

As Stuart J. Murray noted in a comment on an earlier version of this essay, for Foucault, “letting die” is conjoined with making live as “its morbid precondition.”
Robert and Mary Schindler, had been going on for over a decade. Terri Schiavo suffered cardiac arrest and brain damage as a result of lack of oxygen to her brain on February 25, 1990. The apparent cause was a potassium imbalance, which was perhaps the result of an eating disorder. From 1990 until her death in 2005, Terri Schiavo was kept alive by feeding her through a percutaneous endoscopic gastronomy (PEG) tube. In 1992, Terri Schiavo was awarded over $1.25 million in malpractice suits brought against two different doctors. Michael Schiavo received some of this award, and $750,000 was placed in a trust for Schiavo’s care. Disagreements between her parents and husband regarding appropriate care emerged shortly after the money was awarded, and the long legal saga began in 1993 with the Schindlers’ first of many attempts to remove Michael Schiavo as guardian, despite the fact that they had not initially questioned this legal arrangement. In 1998, Michael Schiavo first petitioned to have his wife’s feeding tube removed. Following many appeals, Schiavo’s tube was removed under court order for several days in April 2001, before it was ordered that the tube be put back in. The feeding tube was again removed for several days in October 2003, which prompted the Florida State legislature to pass “Terri’s Law,” and Governor Jeb Bush to issue an executive order directing the reinsertion of the tube. In 2004, the Florida Supreme Court affirmed a lower court decision declaring “Terri’s Law” unconstitutional. In 2005, a story that had remained for the most part localized

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18 The University of Miami Ethics Programs website provides an incredibly useful collection of “Schiavo Case Resources,” including a 24-page timeline of “Key events in the case of Theresa Marie Schiavo,” compiled by Kathy Cerminara of the Shepard Broad Law Center at Nova Southeastern University and Kenneth Goodman of the University of Miami Ethics Programs (http://www.miami.edu/index.php/ethics/projects/schiavo/; accessed September 7, 2011). The timeline is a fairly straightforward account of the countless legal actions taken by both sides in the case, with what I read as a mostly understated support for Michael Schiavo’s position as legal guardian. This support is more obvious when one notices that Cerminara and Goodman are two of the signers of a statement from bioethicists at six Florida universities analyzing the ethical aspects of Florida House Bill 701, and determining, among other things, that the proposed bill, “Would impose impossible burdens on physicians and patient surrogates, proxies and guardians,” “Florida Ethics Leaders’ Analysis on HB 701, March 7, 2005,” (http://www6.miami.edu/ethics/schiavo/pdf_files/030805-HB701-EthicsAnalysis.pdf; accessed September 9, 2010). There are, however, several somewhat odd glosses to the otherwise straightforward timeline, such as the addition to the entry about Terri Schindler and Michael Schiavo’s marriage on November 10, 1984 that tells us, “The union is now among the ‘celebrity marriages’ featured at About.com, a website about marriage.”

19 Interestingly, the timeline on the University of Miami Ethics Programs website does not mention some of the speculation about what led to Schiavo’s cardiac arrest in 1990.

in the state of Florida became a national—even international—event.\textsuperscript{21} I contend that it was George W. Bush’s re-election in 2004, with the strong support of a large number of religious conservatives, a voting bloc widely reported to have swung the election to Bush, which explains, at least in part, the sudden barrage of media reports on the Schiavo story in the U.S. media in 2005. I want to look at one small story in this much larger, longer story in order to examine the Terri Schiavo case as a mediatized case of making live and letting die.

On March 17, 2005, Senator Bill Frist took to the Senate floor to publicly discuss the Terri Schiavo case.\textsuperscript{22} From the beginning, he asserted his credentials, noting that he was “speaking more as a physician than as a U.S. Senator.”\textsuperscript{23} His testimony is a fascinating example of what I call, paraphrasing Bruno Latour, “medicine in action,”\textsuperscript{24} partly because in this instance medicine happened in a place we generally do not expect to see it happen, not in the privacy of the clinic but in the public spaces of Congress, and through mediatization, into our living rooms. Frist himself uses the term “fascinating” to describe the “course of events for us over the last 48 hours,” and admits to wanting “to know more about the case from a medical standpoint,” after having seen newspaper reports. In a lengthy discussion of persistent vegetative state that includes references to \textit{Harrison’s Principles of Internal Medicine}, Frist returns again and again to one key issue: the temporality of diagnosis. He asserts that while brain death is a clear, unequivocal diagnosis, “short of brain death” things are more complicated, and that distinguishing between the categories “coma,” “minimally conscious state,” and “persistent vegetative state” requires “a series of evaluations over a period of time because of fluctuating consciousness.”\textsuperscript{25} Frist’s distinction between “brain death” and “short of brain death” demonstrates quite evocatively, I think, the threshold

\textsuperscript{21} Searches in the Lexis-Nexis database demonstrate quantitatively that the story became a national media event only in 2005. Searches for the key term “Terri Schiavo” show the following: before January 1, 2000, only two articles appeared, both in the \textit{St. Petersburg Times}; from January 1, 2000 to December 31, 2001, there are 103 results, 95 of which are in the \textit{St. Petersburg Times}; from January 1, 2002 to December 31, 2003, 369 newspaper articles appear, 156 in the \textit{St. Petersburg Times}; between January 1 and December 31, 2004, 134 articles appear, 73 in the \textit{St. Petersburg Times}; and between January 1 and December 2005, 2844 newspaper articles appear, 439 from the \textit{St. Petersburg Times}. Searches in Lexis-Nexis database on September 9, 2010.


\textsuperscript{23} Frist, “Terri Schiavo,” S3090.

\textsuperscript{24} I derive the phrase and concept “medicine in action” from Latour’s science studies classic, \textit{Science in Action} (Cambridge: Harvard University Press, 1987).

\textsuperscript{25} Frist, “Terri Schiavo,” S3090.
conditions and mobile boundaries between categories that interested both Foucault and Agamben.

Frist further establishes his authority to determine what is “brain death” and what is “short of brain death” in the Schiavo case by discussing his experience as a transplant surgeon and former director of the transplant center at Vanderbilt University. He explains the procedures for procuring organs for transplant in this way: “in each and every case when you do a heart transplant or a lung transplant or a heart-lung transplant, the transplanted organs come from someone who is brain dead and death is clearly defined with a series of standardized clinical exams over a period of time, as well as diagnostic tests.”

What he doesn’t say in this context is that the time of diagnosis of brain death in the U.S. is now usually only six hours, and can, in some instances, be shortened to only two hours, between clinical exams, according to guidelines for determining brain death. What Frist also doesn’t say is that the diagnostic category “brain death” is not perceived as quite so clear and uncontroversial in many places outside the U.S. In *Twice Dead*, the medical anthropologist Margaret Lock discusses the historical emergence of the diagnostic category “brain dead,” and provides a revealing comparative history of organ procurement and transplantation in North America and Japan. Lock’s historical and comparative analysis calls into question Frist’s neat and tidy assessment that this is a “clear, unequivocal diagnosis.”

Lock discusses the advances in medical technologies, including the invention of the artificial ventilator, as well as the legal recognition (in the United States, though not in Japan) of a new category of death. Lock argues that death is not “an indisputable biological event,” and that “margins between life and death are socially and culturally constructed, mobile, multiple, and open to dispute and reformulation.” And Lock, along with Agamben, notes the “historical coincidence that was perhaps accidental,” in Agamben’s assessment, that saw advances in life-support technologies and transplant technologies that made necessary a redefinition of death.

Once Frist has established his expertise in determining categories of consciousness and death, he admits to being “a little bit surprised to hear a decision had been made to starve to death a woman based on a clinical exam that took place over a very short period of time by a neurologist who was called in to make the diagnosis rather than over a longer period of time.” According to

26 Ibid.
28 Lock, *Twice Dead*, 4 and 11.
Frist, diagnoses take time, and although the initial incident that led to Schiavo’s condition in 2005 occurred in 1990, Frist argues that Schiavo has not been properly diagnosed because she has not been diagnosed over time. This sounds very much like the sort of argument that many disability activists and scholars make in response to many non-disabled people’s certainty that they would rather die than be paralyzed, or blind, or live with other disabling conditions. The problem is epistemological and temporal. How does one know how one will react to the loss of function or ability until one finds oneself in that particular situation of loss? And how do one’s feelings change as the situation of loss changes, as it surely will for physical, emotional, economic, and social reasons?

In Schiavo’s case, of course, there is also the cognitive question about what she herself knows and doesn’t know, or is aware of or not, again, over time. Moreover, her experience of disability is never only her own. Schiavo’s experience of disability—whether she has a cognitive understanding of it or not—happens in relation to others—her family, carers, and, in Schiavo’s case in 2005 and after, the public. This too must be measured over time, and cannot be demarcated in any simple way. A disability studies perspective extends and

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30 Many autobiographical accounts by people with disabilities emphasize this point. See, for example, John Hockenberry, Moving Violations: War Zones, Wheelchairs, and Declarations of Independence (New York: Hyperion, 1996); Stephen Kuusisto, Planet of the Blind: A Memoir (New York: Delta, 1998); and Nancy Mairs, Waist-high in the World: A Life Among the Nondisabled (Boston: Beacon Press, 1998). Disability rights activists were, of course, some of the most committed supporters of Schiavo’s parents’ attempts to prevent her feeding tube from being removed. In 2004, Not Dead Yet and other disability rights organizations filed an amicus brief in the case of Jeb Bush (Governor of the State of Florida) v. Michael Schiavo (Guardian of the Person of Theresa Marie Schiavo) in support of the governor’s and legislature’s attempts to reverse the court decision in 2004 to remove Terri Schiavo’s feeding tube. The brief argues that in the case of Terri Schiavo, the legislation “reverses only the consequence of a judgment for an incapacitated woman who may not want to die,” http://www.notdeadyet.org/docs/bushvsschiavoamicus.html (accessed September 12, 2010).

31 For a fascinating example of how the experience of disability changes over time for the person who is disabled and for her or his family, see Anne Fadiman, The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures (New York: Farrar, Straus and Giroux, 1997). Part of the “collision of cultures” that this text demonstrates is the sharply contrasting ways that the American and Hmong cultures handle Lia Lee’s declining condition. Eventually diagnosed as in a “persistent vegetative state,” Fadiman writes that, “[f]or more than two years, her doctors had been waiting for her to die, and her parents had been confusing them with their ability to keep her alive. Although Lia was not dead, she was quadriplegic, spastic, incontinent, and incapable of purposeful movement” (210). And yet, her parents were able to continue feeding her without intervention. For more on the way the multiple experiences and events of cognitive disabilities challenge the emphasis on rationality in medicine and bioethics, see the work of Eva Feder Kittay and Licia Carlson,
complicates the practices of diagnosis and treatment, demonstrating that these are not simply medical, but also social, practices.

Yet, just when it looks like Frist might complicate our understanding of Schiavo’s situation in particular and cognitive disability in general, he insists his own expertise allows him to see clearly what is more opaque to others, who have not been trained to see as he has. Immediately undercutting his own argument about the difficulty of diagnosis and his call to extend the time of diagnosis in this case, Frist then makes his own diagnosis on the Senate floor based on the videotape provided to the media by Schiavo’s parents. Unaware or unconcerned that he is contradicting his own repeated assertions, Frist makes this statement: “Persistent vegetative state, which is what the court has ruled, I say that I question it based on a review of the video footage which I spent an hour or so looking at last night in my office here in the Capitol. And that footage, to me, depicted something very different than persistent vegetative state.” Immediately after this statement, Frist cites the 16th edition of Harrison’s textbook, which he defends as authoritative and up-to-date (it “was published just this year, 2005,” he notes), to help him read the video footage, which he also reminds us “is the actual exam by the neurologist.” There are multiple genres and effects of mediatization at work here, beginning with the neurologist’s exam performed on camera, precisely so that the exam itself might circulate as evidence beyond the private space of the clinic.

Senator Frist was widely chastised and even ridiculed for his diagnosis of Schiavo via videotape, and also for his taking up of the case in the hopes of breathing life into his own political career. I want to bring up a slightly different critique here, however. Frist tells us we must diagnose Schiavo over time, and then proceeds to interpret a short video of Schiavo as though it provides sufficient evidence to make a diagnosis. What I’m concerned with is not so much the obvious contradiction in Frist’s own diagnosis. The Schiavo case is clearly about the inextricable link between politics and medicine, and this link is revealed in all the twists and turns of the case, including its mediatization in 2005. What is missing from Frist’s diagnosis of Schiavo, and also from the criticism of him, is a problematization of the visual evidence, the medical evidence, and temporality—and the inextricable relationship between these
three things. What did we see and not see—in the video in particular and in the mediatized medical event of the Terri Schiavo case in 2005 in general? Although the videotape certainly generated sympathy and support for Schiavo’s parents from some sectors of the American population, I would argue that, more generally, the videotape, parts of which were shown over and over on cable television, often in a constant loop, worked against Schiavo’s parents’ attempts to prove that their daughter was responsive—cognitively and emotionally—to them. Instead, as is signaled by the upsurge in living wills that resulted from this mediatized medical event, even more than sympathy and support, the videotape appears to have generated fear among a large segment of the U.S. population, as members of the public imagined themselves or their loved ones in Schiavo’s position, and found terrifying the possibility of becoming a public spectacle as they saw Schiavo become. The iteration and reiteration of Schiavo on videotape sedimented rather than complicated the public’s interpretation of Schiavo’s condition as permanent and unchanging, and led them to create advance directives in order to protect themselves and their families from such an experience and, perhaps most importantly, from such a public scene.

While I think Frist makes an important point regarding the temporality of diagnosis, I also think his analysis falls short, foreshortened as it is by his own faith in his capacity to determine whether or not Schiavo is in a persistent vegetative state based on his examination of the video evidence. The spectacle of Frist’s decisive diagnosis is misleading, not in the simple sense that it is either right or wrong, but because it too participates in the emergency time of state power. By asserting his expertise as a doctor, especially a transplant doctor trained in determining brain death, and by practicing medicine in the context of the U.S. Congress and not the clinic, Frist, unwittingly, conjures a specter of what Agamben calls “the medical politics of the Reich.” I want to tread carefully here. I am not arguing that Frist’s position, or the conservative position on the Terri Schiavo case more generally, should be likened to Nazi

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33 Agamben, 1998, 144.
medico-politics. And, indeed, considering that the conservative position here, at
least rhetorically, emphasizes the value of all human life rather than making
distinctions, as the Nazis did, between lives worth living and those deemed not
worth living, it should be clear that any comparison with Nazism does more to
simplify than complicate the difficult ethical questions that the case thematizes.
Still, as should be clear from my earlier discussion of the Bush Administration’s “culture of life,” I take the “right-to-life” politics articulated by the religious right in the United States as participating in the exercise of biopower in its individualizing and massifying modes, rather than opposed to, or abstaining from, its exercise. As Foucault showed in his discussion of the emergence of biopower, life itself becomes an object of power, and in many ways the political right in the U.S. has been more adept than the left at practicing a medico-politics under the cover of a religio-cultural rhetoric—

hence the Bush Administration’s culture, not politics, of life.34

What I am concerned with here is the way that Frist’s performance makes visible what Agamben describes as “one of the essential characteristics of modern biopolitics”—“the integration of medicine and politics.”35 According to Agamben, in modern biopolitics, as perhaps best exemplified in the medical practices of the Nazis, “the sovereign decision on bare life comes to be displaced from strictly political motivations and areas to a more ambiguous terrain in which the physician and the sovereign seem to exchange roles.”36 By emphasizing his dual role as physician and senator, Frist makes less ambiguous the interconnectedness between medical and political motivations, and, paradoxically, undermines his authority in both the medical and political domains. Politics, medicine, and media converge in the public scenes of the diagnosis of Terri Schiavo, and Frist, for one, is surprised not to be able to control the effects of this exercise of biopower in a bioconvergent field. In the mediatized medical event of the battle over Terri Schiavo’s life and eventual death by starvation, biopower in its individualizing mode is demonstrated. This becomes especially apparent when the state of Florida passed, and the federal government attempted to pass, laws not just in her name after her death, as in the case of, for example, Megan’s Law, which requires that information be made publicly available about where convicted sex offenders live, but in order to bring all legal, technological, political, and social resources to bear in order to keep her alive. “Terri’s Law” was not a law that bore Schiavo’s name as

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35 Agamben, 1998, 143.
36 Ibid.
representative of a class of citizens, it was a law that sought to keep her—and only her—alive. Terri Schiavo becomes an exemplary case of the Bush Administration’s “culture of life”—a culture that comes into being, paradoxically, through practices of individualization rather than by creating affinities between and among different peoples. Schiavo is individualized in and by the media event surrounding her case. She is both spectacularized and personalized, and we come to think we know something about who she is or was, and about her relationships with her parents, brother, and husband. This presumed knowingness contrasts sharply with the other spectacle of biopolitics from 2005—the letting die of populations in the wake of Hurricane Katrina. The death of populations is the other side of the “culture of life,” and even as the letting die comes fleetingly into view in a case like Hurricane Katrina and its aftermath, it is also always already becoming de-personalized and disappearing from our “circle of moral concern.”

**Medicine in action 2: Speeding up slow deaths**

If the Terri Schiavo case is an example of the practices of making live and letting die in biopower’s individualizing mode, Hurricane Katrina and its aftermath is an example of the practices of letting die in its massifying mode. Within this mode of biopower as Foucault describes it, racism becomes the justification for “the need to kill people, to kill populations, and to kill civilizations.” As Foucault asserts, “When I say ‘killing,’ I obviously do not mean simply murder as such, but also every form of indirect murder: the fact of exposing someone to death, increasing the risk of death for some people, or, quite simply, political death, expulsion, rejection, and so on.” Achille Mbembe’s influential essay “Necropolitics” builds on both Foucault’s and Agamben’s analyses of biopower, and, like Agamben’s work, corrects the misreading of Foucault that states that biopower replaces sovereign power. According to Mbembe, “to kill or to allow to live constitute the limits of sovereignty, its fundamental attributes. To exercise sovereignty is to exercise control over mortality and to define life as the deployment and manifestation of power.” Mbembe’s analysis of necropolitics is especially useful to me.

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37 Foucault, 2003, 257.
38 Foucault, 2003, 256.
39 Achille Mbembe, “Necropolitics,” trans. Libby Meintjes, Public Culture 15.1 (2003), 11-12. Some commentators have read Mbembe’s work and concept of necropolitics as fundamentally transforming Foucault’s concept of biopower. But, like Agamben, Mbembe does not so much overturn Foucault’s concept as make use of it in order to help him investigate the figure of the slave and the technologies of slavery and colonization.
because he makes clear in his first footnote that his “essay distances itself from traditional accounts of sovereignty found in the discipline of political science and the subdiscipline of international relations. For the most part,” Mbembe continues, “these accounts locate sovereignty within the boundaries of the nation-state, within institutions empowered by the state, or within supranational institutions and networks.”

In his classic delineation of what he calls the “risk society,” Ulrich Beck heralds the growing presence and importance of “the risk experts,” who “proclaim what one need fear and what one need not fear,” and in the case of the response to Hurricane Katrina, Beck’s much earlier description of an emergent social configuration proved prescient. As I will argue in detail at the end of this essay, sovereignty in a risk society is located in those persons who are in a position to make determinations about risk, who are able to assess, and at the same time, to avoid risk. According to Beck, “the society of risk is also a catastrophe society. In it, a state of emergency threatens to become a normal state.”

Many people have commented at length on the failures of the U.S. state to respond adequately to the devastation of Hurricane Katrina, and many have also pointed to the state racism and classism that, in one sense, so obviously explains this failure, and, in another sense, hides as much as it reveals in its pat, ready-to-hand formulations. As with the Schiavo case, I want to shift the focus slightly by looking at the ways Katrina too was a mediatized medical event that, in the circulation of images of the event, made visible to the U.S. population in general the usually hidden effects of what Foucault called an endemic, by which he meant deaths that become naturalized and are deemed unpreventable. In this sense, we might consider Hurricane Katrina as

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40 Mbembe, 2003, 11.
42 Beck, 1990, 55.
44 Spike Lee’s four-part documentary for HBO, *When the Levees Broke* (2006), takes a long look at the historical, economic, and social conditions that led to the levees breaking. According to Lloyd Pratt, in an introduction to a special issue of *differences* on “the event,” Lee’s film “represents a deliberate response to the naturalizing, ‘de-eventing’ of what happened in New Orleans.” Lloyd Pratt, “In the Event: An Introduction,” *differences: A Journal of Feminist Cultural Studies* 19.2 (2008), 5. For an analysis that makes a very useful strategic link between Hurricane Katrina and another supposedly “natural” disaster, the eruption of Mt. Pinatubo in the Philippines in 1991, see the brilliant concluding chapter, “‘Death Was Swiftly Running After
exemplifying medicine in inaction. But, as we are only learning now, belatedly
and haltingly, this vision of Hurricane Katrina as a demonstration of the
shocking failures of the U.S. state is something of a comforting illusion that
covers over a less comforting story that signals for me a re-assertion of medical
sovereignty via the discourses, practices, and institutions of crisis management.
The mediatization of Hurricane Katrina and its aftermath enacts the
convergence of sovereign power and biopower, and crisis management is the
key modality of this bioconvergent mediatized power.

In a recent piece of investigative journalism, “The Deadly Choices at
Memorial,” first published on the webpage of the newly formed non-profit
news organization, ProPublica, and also published in the New York Times
Magazine on August 20, 2009, Sheri Fink revisits the crisis conditions at
Memorial Hospital, a public hospital in New Orleans, and argues that these
crisis conditions became the justification for the killing of particular
populations—the sick, disabled, and obese. This investigation into the events
at Memorial Hospital during the period immediately following the hurricane
suggests that sovereignty was not undermined, but emboldened by the crisis,
and I contend that this emboldened exercise of medical sovereignty is a
condition of emergency time; or, perhaps it is more accurate to say, medical
sovereignty is the desired outcome of emergency time. Importantly, then, the
investigation also does something more: it demonstrates another temporality of
crisis by extending the time of emergency through the practices of investigative
journalism.

In its statement of purpose, ProPublica explains and justifies its own
emergence in 2008 in temporal terms. “Why Now?” it asks, and, in response,
explains that,

Profit-margin expectations and short-term stock market
concerns, in particular, are making it increasingly difficult for
the public companies that control nearly all of our nation’s news
organizations to afford—or at least to think they can afford—the
sort of intensive, extensive and uncertain efforts that produce

Us”: Disaster, Evil, and Radical Possibility,” in Dylan Rodriguez, Suspended Apocalypse:
White Supremacy, Genocide, and the Filipino Condition (Minneapolis and London: University
of Minnesota Press, 2010).

46 Sheri Fink won a 2010 Pulitzer Prize for Investigative Reporting for her coverage of the
events at Memorial Hospital in the wake of Hurricane Katrina.
great investigative journalism. The ProPublica statement goes on to explain that, as a form, investigative journalism requires “a great deal of time and labor to do well … because the ‘prospecting’ necessary for such stories inevitably yields a substantial number of ‘dry holes,’” or what we might call failed stories.

“The Deadly Choices at Memorial” attempts to explain how and why 45 people died at Memorial Medical Center in New Orleans after Hurricane Katrina, “more than from any comparable-size hospital in the drowned city.” Were these extremely sick and elderly patients simply the victims of this catastrophic event? Did they simply run out of time, as they and countless others were left for days waiting to be rescued from a flooded hospital without power or sufficient provisions? Or did doctors, who were in the untenable position of deciding who should be rescued first, speed their deaths by categorizing some as savable and others as not, and injecting lethal doses of drugs into those deemed not savable? On the one hand, this is clearly a case of “letting die” as Foucault describes it: the most vulnerable exposed to harsh conditions, their options severely circumscribed by the state’s inaction. In this scenario, the doctors and nurses who endured the same conditions in an attempt to give care and save lives, might be seen as acting heroically to prevent the

49 In “Waiting-to-death, or Security and Asylum-Seeking in a Hospital ER,” Victoria Pitts-Taylor presents a harrowing account of the death of Esmin Green in the waiting room of the psychiatric ER at Kings County Hospital in Brooklyn. Harrowing because Green spent twenty-four hours in the waiting room ignored by staff and security guards. Even when she collapsed to the floor, she continued to be ignored for over thirty minutes before a nurse nudged her with her foot, apparently as a means of determining if she was still alive. Pitts-Taylor cites a New York Daily News article that details the last hour of Esmin Green’s life, and the irony, along with the horror, is not lost on Pitts-Taylor: “Such a detailed description was made possible because Esmin Green’s death was videotaped. The security cameras, tracking from four different angles, watched and recorded every move of the patient and the staff.” Victoria Pitts-Taylor, “Waiting-to-Death, or Security and Asylum-Seeking in a Hospital ER,” WSQ: Women’s Studies Quarterly 39.1-2 (spring/summer 2011), 340.
50 In 2006, the Louisiana Department of Justice arrested a doctor, Anna Pou, and two nurses, Cheri Landry and Lori Budo, in connection with the deaths of four patients. As Fink explains in her reporting, “After a New Orleans grand jury declined to indict [Pou] on second-degree murder charges, the case faded from view” (Fink, 2009, 30). Until, of course, Fink, through her reporting, reopened the case in the media.
inevitable endemicization of deaths after Hurricane Katrina. But, there is another story to tell, one that has been covered over by both the story of medical heroism and the story of letting die. Interestingly, this seems to me to be a story of both another temporality and another kind of power—a sovereign sort, as I will argue, with the authority to take life.

In her recent essay “Slow Death (Sovereignty, Obesity, Lateral Agency),” Lauren Berlant explores the relationship between temporality, biopower, health, and disability that I am also trying to grapple with here, although her object is different from mine. Her ultimate purpose is to challenge the temporality of crisis that certain events instantiate, and she does this by shifting her focus from moments of crisis, in all their eventfulness, to everyday episodes, in all their ongoingness, what she calls “the pragmatic (life-making) and accretive (life-building) gestures and … the relation of that activity to the attrition of the subject.” Such ongoing, everyday episodes tend not to be mediatized, or, as happens in the iterative practices of reality TV or many day-time talk shows, by spectacularizing the everyday. Berlant wants to think about the different ways power is exercised, and, like Foucault, she argues that the concept of sovereignty does not really capture the practice of agency in daily life. And yet, Berlant’s description of sovereignty does seem to capture the power exercised by some of the medical staff at Memorial Hospital in the aftermath of Hurricane Katrina. For Berlant, sovereignty encourages a militaristic and melodramatic view of agency in the spectacular temporality of the event of the decision; and, in linking and inflating consciousness, intention, and decision or event, it has provided an alibi for normative governmentality and justified moralizing against inconvenient human activity.

At Memorial Hospital, certain medical practitioners took it upon themselves to determine the temporal parameters of the emergency; through their actions in the “spectacular temporality of the event of the decision” they asserted the sovereignty of medicine in the disaster. How did they do this? By deciding, without consultation with rescuers, that certain patients could not—or would not—be rescued.

Two types of patients seem to have been singled out as not resuscuable: those patients with do not resuscitate (D.N.R.) orders and those patients who were obese. As Fink reports, a group of doctors at Memorial decided early on

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51 Lauren Berlant, “Slow Death (Sovereignty, Obesity, Lateral Agency),” Critical Inquiry 33 (summer 2007), 757. Berlant’s essay is part of a special issue on the case study.
that people with D.N.R. orders would be among the last evacuated. Fink explains that a D.N.R. order “means one thing: A patient whose heartbeat or breathing has stopped should not be revived.” Yet, Richard Deichmann, the hospital’s medical-department chairman, tells Fink that, “patients with D.N.R. orders had terminal or irreversible conditions,” and that “he believed they would have had the ‘least to lose’ compared with other patients if calamity struck.” It seems doctors mistakenly interpreted these advance directives as about the patient’s immediate condition and will (or not) to live (in the event of a hurricane), rather than as an attempt on the part of the patient to maintain control over the actions of medical practitioners in certain critical situations. The irony is that in this instance the D.N.R order gave the patients less, not more, control. In this case of the event of the decision, D.N.R. became “do not rescue,” “do not treat,” and “do euthanize.” Considering that do not resuscitate orders emerged historically as a result of a battle over who—doctors or patients and their families—makes decisions about end-of-life care, the interpretation by doctors in this instance might be read as a kind of willful obtuseness covering over a punitive response to an assertion of autonomy on the part of patients. And considering that the issue of advance directives had been in the news only months before because of the denouement of the Terri Schiavo case, one can begin to discern direct links between the two mediatized medical events that I have brought together in this essay.

In the cases of Emmett Everett and Rodney Scott, two patients discussed by Fink in “The Deadly Choices at Memorial,” the decision about whether or not to evacuate them seemed to have everything to do with their obesity, and the judgment that they were too much of a burden, both literally and figuratively, for the doctors and nurses to carry. Although this was rationalized as a physical judgment, in the sense that doctors and nurses did not believe they could physically carry them up the stairs that led to the helicopter

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54 Ibid.
55 The question of the patient’s desires in the case of extreme cognitive and physical incapacitation was also an issue in the Schiavo case. Michael Schiavo’s assertion that he and Terri had discussed her wish not to be kept alive should she become permanently incapacitated was one of the cornerstones of his legal argument to have her feeding tube removed. For an historical analysis of the emergence of the field of bioethics, and a discussion of the centrality of the Karen Ann Quinlan case and the formulation of advance directives to the field, see David J. Rothman, Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making (New York: Basic Books, 1991). The date of Schiavo’s death in 2005, March 31, is the same date in 1976 that the New Jersey Supreme Court ruled that Karen Ann Quinlan could be disconnected from her respirator, as noted in the timeline of “Key events in the case of Theresa Marie Schiavo” (op. cit.). Quinlan did not die until 1985.
pad, the fact that they never tried with Everett and were ultimately able to do so with Scott, belies the rationality of this judgment. In her essay “Slow Death,” Berlant discusses the phrase “morbidly obese,” and the fact that this phrase “seems so frequently to raise the African-American specter in ways that reinforce the image of African Americans as a population already saturated by death and available for mourning, compelled by appetites rather than by strategies of sovereign agency toward class mobility.”56 One might question the association Berlant makes between race and morbid obesity, and her image of African Americans as a population is too monolithic. Isn’t class, not race, the unifying characteristic? Yet, what we saw in the mediatized medical event of Katrina was precisely the specter Berlant describes. What were and are the repercussions of such an event? How do we extend the story beyond the moment of crisis when death for some was perceived and presented as a rational choice?

In the crisis at Memorial in the aftermath of Katrina, doctors and nurses deemed the morbidly obese unsavable, and rather than simply letting them die, it appears they speeded up their deaths. This, it seems, was crisis management; and the doctors at Memorial were the crisis managers, those lonely sovereign agents making life and death decisions. The last—at least for the moment—twist in this tale is that Anna Pou, who helped so many patients “through their pain” by giving them lethal injections of pain medication, has become one of the key advocates for “changing the standards of medical care in emergencies” in order to protect the crisis managers from the burdens—ethical and legal—of their decisions.57 As Fink explains, “Pou has helped write and pass three laws in Louisiana that offer immunity to health care professionals from most civil law suits—though not in case of willful misconduct—for their work in future disasters, from hurricanes to terrorist attacks to pandemic influenza.”58

Conclusion: Becoming immune

The cases of Schiavo and Katrina gave us a glimpse into the production of biopower as the activity of sovereign power. These cases suggest the question is not, or not only, when or how did biopower surpass sovereign power, but who gets to claim sovereign agency in the enactment of biopower? By prolonging and therefore normalizing the time of emergency through the practices of crisis management, medicine expands its power to make live and let die. In the time

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56 Berlant, 2007, 774.
57 Fink, 2009, 30.
58 Ibid.
of emergency, it seems, we revert to an older form of power, that of sovereignty, in this case a medical sovereignty, which produces the biopolitical body (both individually and socially) through the practices of crisis management, and which remains above the law through a condition of immunity that is naturalized. In his recent book *A Body Worth Defending: Immunity, Biopolitics, and the Apotheosis of the Modern Body*, Ed Cohen offers a genealogy of the concept and practices of “immunity.” Cohen explores immunity’s “hybridity,” bringing together one of Bruno Latour’s key concepts with Foucault’s genealogical method to create his own impure theory/method hybrid that opens up the conditions of possibility for other ways of understanding the modern body beyond the “immunity-as-defense” paradigm. Cohen notes that immunity was not originally a biological concept, but that the concept migrated from politics and law into medicine. Biological immunity only arrived on the scene in the late nineteenth century. Why and how this conceptual migration came about is one of Cohen’s key questions, not simply to make a causal argument about the disciplinary origins of a concept, but also to ask a question about effects: “how did we come to believe that as living beings, ‘the body’ separates us from each other and from the world rather than connects us?”

One effect that Cohen doesn’t mention is the immunity of doctors through the convergence of law and medicine in the practice of bioethics. Since its emergence in the 1970s, bioethics, like medicine itself, has become increasingly concerned with rationalizing the use of medical procedures and technologies, and managing the risks of such procedures and technologies most effectively. Or, put differently, bioethics is one of the key means by which medicine rationalizes the reduction of its scope, and becomes immune, in both the legal and figurative sense: “Exempt from a charge or burden; free (from liability, obligation, or penalty); not legally subject (to a jurisdiction, law, etc.)” and “Wholly protected (from something injurious or distasteful); not susceptible or responsive (to something).” By taking another look at two seemingly divergent events from 2005, my hope is to expand the space and extend the time of the project of bioethics—that is, to make medicine more susceptible and responsive, not less so. Taking account of the multiple spaces and temporalities of medicine complicates the practice of medicine, and attempting to account for complexity seems to me to be the most important task of ethics.

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