

Biopolitics at the Bedside: Proxy Wars and Feeding Tubes Joshua E. Perry¹

Abstract

In the aftermath of Terri Schiavo's dramatic final weeks of life, George Annas speculated that proponents of "culture of life" politics might "now view [themselves] as strong enough to generate new laws . . . to require that incompetent patients be kept alive with artificially delivered fluids and nutrition." Indeed, Professor Annas' prescience has been demonstrated by the post-*Schiavo* introduction in two dozen state legislatures of over fifty different bills making it more onerous to remove a patient's artificial nutrition and hydration (ANH). With minor exception, however, most of the proposed legislation has either stalled or been watered down, prompting columnist Ellen Goodman to ponder: "What if they gave a culture war and nobody came?" With public opinion polls reporting large majorities in favor of Mrs. Schiavo's right to cease ANH and in opposition to the government's intervention in Mrs. Schiavo's case, the failure of this legislative agenda is not surprising. But Ms. Goodman's query underestimates the power of what Alta Charo labels "proxy wars" waged by well-funded, opportunistic abortion opponents who seized on the *Schiavo* case as an opportunity "to rehearse arguments on the value of biologic but nonsentient human existence." Appropriating Professor Charo's notion of "proxy wars" and various critical theorists' concept of biopolitics—that political power which Foucault labeled "the power to 'make' live and 'let' die"—this paper explores the post-*Schiavo* political-legal environment and the surge in ANH-related legislation as evidence of what Nancy Neveloff Dubler has termed "a new era of politicized and polarized death."

Introduction

In the introductory essay to the June 2006 issue of the *Journal of Medicine and Philosophy*, Jeffrey P. Bishop and Fabrice Jotterand note that "bioethics has always been a biopolitics and the political dimension is only now coming into relief for bioethicists."² Writing in the May-June 2006 issue of the *Hastings Center Report*, Jeff Kahn echoes this sentiment when he comments that "[b]ioethics has always been involved in policy issues and the politics surrounding them."³ So despite a history of political intersections, why

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² Jeffrey P. Bishop & Fabrice Jotterand, *Bioethics as Biopolitics*, 31 JOURNAL OF MEDICINE AND PHILOSOPHY 205, 205 (2006).

³ Jeffrey P. Kahn, *What Happens When Politics Discovers Bioethics?*, 36 HASTINGS CENTER REPORT 3:10 (May-June 2006).

has bioethics and its entanglement with politics only recently arrested the attention of so many commentators?⁴

One compelling answer suggested by Jonathan Moreno, Art Caplan and Alta Charo focuses on the event of the President's Council on Bioethics (PCB).⁵ In the wake of a bitterly contested electoral process that gave rise to an acerbically partisan polity, President Bush announced the creation of the PCB in August 2001, during the same speech (his first primetime address to the nation) in which he proclaimed his position on cloning research and his decision regarding federal funding of embryonic stem cell research. Birthed in what Leon Kass terms "embryoville" and labeled by many as the "stem cell council," the PCB has never successfully distanced itself from highly political subject matter.⁶ Indeed, despite former chairman Kass's protestations to the contrary, evidence suggests that the PCB itself has incorporated politics into its work to an unprecedented degree with "a concerted effort to promote a particular political philosophy" through both "its membership and its staffing."⁷

⁴ For a sampling of the recent literature discussing bioethics and politics, see generally Ruth Macklin, *The New Conservatives in Bioethics: Who Are They and What Do They Seek?* 36 HASTINGS CENTER REPORT 1:34-43 (Jan.-Feb. 2006); Eric Cohen, *Conservative Bioethics & the Search for Wisdom*, 36 HASTINGS CENTER REPORT 1:44-56 (Jan.-Feb. 2006); Leon R. Kass, *Reflections on Public Bioethics: A View from the Trenches*, 15 KENNEDY INSTITUTE OF ETHICS JOURNAL 221-250 (2005); Madison Powers, *Bioethics as Politics: The Limits of Moral Expertise*, 15 KENNEDY INSTITUTE OF ETHICS JOURNAL 305-322 (2005); R. Alta Charo, *Realbioethik*, 35 HASTINGS CENTER REPORT 4:13-14 (July-Aug. 2005); Arthur Caplan, "Who Lost China?" *A Foreshadowing of Today's Ideological Disputes in Bioethics*, 35 HASTINGS CENTER REPORT 3:12-13 (May-June 2005); Jonathan D. Moreno, *The End of the Great Bioethics Compromise*, 35 HASTINGS CENTER REPORT 1:14-15 (Jan.-Feb. 2005); R. Alta Charo, *Passing on the Right: Conservative Bioethics is Closer Than It Appears*, 32 JOURNAL OF LAW, MEDICINE & ETHICS 307 (2004); Leigh Turner, *Science, Politics and the President's Council on Bioethics*, 22 NATURE BIOTECHNOLOGY 509-510 (2004); Yuval Levin, *The Paradox of Conservative Bioethics*, 1 THE NEW ATLANTIS 53-65 (2003).

⁵ Caplan, "Who Lost China?" at 12; Moreno, *The End* at 15; Charo, *Passing on the Right* at 307.

⁶ Kass, *Reflections on Public Bioethics*, at 223.

⁷ Charo, *Passing on the Right* at 308. But see Kass, *Reflections on Public Bioethics* at 225-226 ("The Council is, by design, in every respect a diverse and heterogeneous group. By training we are scientists and physicians, lawyers and social scientists, humanists and theologians; by political leaning we are liberals and conservatives, Republicans, Democrats, and independents; and by religion we are Protestants, Catholics, Jews, and perhaps some who are none of the above. . . . I hasten to add that there were no political or ideological litmus tests for appointment to the Council, not the first time around, and not at the start of our

I find the PCB thesis to be largely correct in helping to explain the most recent manifestation of bioethics' politicization. The PCB thesis, however, fails to explain fully this “new era of politicized and polarized *death*.”⁸ In an attempt to understand better the recent fusion of politics and feeding tubes at the end of life, this paper develops an additional explanation—the “proxy war”⁹ thesis, which is slightly different although certainly related to the political shadows cast by the PCB. In short, the proxy war thesis is rooted in “a new political and moral agenda that sees the ‘right to life’ as applying both to the beginning and to the end of existence” and envisions a culture of control over the bodies of individual citizens.¹⁰

This paper begins with a discussion of biopolitics—that political power which Foucault labeled “the power to ‘make’ live and ‘let’ die” and an exploration of how various applications and mutations of this political concept help shed light on the tensions between power, regulation, individual autonomy, and the common good in the context of death and dying.¹¹ As documented in Part II, these tensions have been concretely realized in the widespread introduction of post-*Schiavo* legislation designed to make it

second term. Of the original 18 members, probably seven or eight did not vote for President Bush, and no one asked. Nor was there ever any litmus test on the embryo questions. It is time to put to rest the libel that the Council is a hyper-politicized group of right-wing fundamentalists, seeking to impose pro-life views on the nation or willing to ignore scientific facts in the name of religious ideology.”)

⁸ Nancy Neveloff Dubler, *Conflict and Consensus at the End of Life*, HASTINGS CENTER REPORT (SPECIAL REPORT: IMPROVING END OF LIFE CARE: WHY HAS IT BEEN SO DIFFICULT?), S19, S23 (2005) (emphasis added). “The Schiavo case reflects the fact that death is the new arena for self-serving professional and partisan preening and for potential political gain. . . . Unfortunately, as the Schiavo case demonstrated, death may be good politics.” *Id.* at S20.

⁹ R. Alta Charo, *The Celestial Fire of Conscience—Refusing to Deliver Medical Care*, 352 NEW ENG. J. MED. 2471, 2471-73 (2005).

¹⁰ Nancy Neveloff Dubler, *Conflict and Consensus at the End of Life*, HASTINGS CENTER REPORT (SPECIAL REPORT: IMPROVING END OF LIFE CARE: WHY HAS IT BEEN SO DIFFICULT?), S19, S19 (2005). I am indebted to Larry Churchill for the clever “culture of control” phraseology.

¹¹ MICHEL FOUCAULT, “SOCIETY MUST BE DEFENDED”: LECTURES AT THE COLLÈGE DE FRANCE, 1975-76 [LECTURES], at 241 (David Macey trans., Mauro Bertani et al. eds., Picador 2003).

more onerous to remove a patient's artificial nutrition and hydration (ANH).¹² With large majorities continuing to oppose the government's intervention in Mrs. Schiavo's situation, it is perhaps not surprising that the vast majority of these proposals have not (yet) succeeded in altering the legal landscape.¹³ Nonetheless, I argue that it is a mistake to dismiss or to ignore these political overtures.¹⁴

Rather, as introduced above and discussed in Part III, biopolitical theory helps crystallize the conversation and provides a framework for discussing the power of what Alta Charo labels "proxy wars."¹⁵ The proxy war thesis best explains why well-funded, opportunistic abortion opponents seized on the *Schiavo* case as an opportunity to "rehearse arguments on the value of biologic but nonsentient human existence," while they moved beyond the political scope of neonates to consider neomorts.¹⁶ In other words, this paper attempts to provide help answering the puzzling question: Why has the beginning-of-life-obsessed anti-abortion movement seized on the issue of end-of-life feeding tubes? Ultimately, this paper concludes that biopolitics in our early 21st century United States context is about the strategies and agendas for controlling and regulating the bodies of individuals even at the bedside as they lay dying. Politicized interventions that seek to control and to regulate the personal and private space of one's final exit—in

¹² Observing the unprecedented drama surrounding Terri Schiavo's final weeks of life, George Annas had speculated that proponents of "culture of life" politics might "now view [themselves] as strong enough to generate new laws . . . to require that incompetent patients be kept alive with artificially delivered fluids and nutrition." See George J. Annas, "Culture of Life" Politics at the Bedside—The Case of Terri Schiavo, 352 NEW ENG. J. MED. 1710, 1710-15 (2005).

¹³ See generally Gary Langer, Poll: No Role for Government in Schiavo Case, ABCNEWS.GO.COM, Mar. 21, 2005, available at <http://abcnews.go.com/Politics/PollVault/story?id=599622&page=1>. Accord Dalia Sussman, More Than Six in 10 Still Support Decision in Schiavo Case, ABCNEWS.GO.COM, Mar. 27, 2006, available at <http://abcnews.go.com/Health/PollVault/story?id=1771492>.

¹⁴ See Ellen Goodman, *Schiavo Debate is Back But Life's Moved On*, THE BOSTON GLOBE, Mar. 31, 2006, at A15 ("What if they gave a culture war and nobody came?").

¹⁵ R. Alta Charo, *The Celestial Fire of Conscience—Refusing to Deliver Medical Care*, 352 NEW ENG. J. MED. 2471, 2471-73 (2005).

¹⁶ *Id.* Neomorts are defined as humans that have permanently lost consciousness but still have functioning bodies. See Willard Gaylin, *Harvesting the Dead*, HARPER'S MAGAZINE, Sept. 23, 1974, at 23-30.

an effort to promote the “culture of life” cliché—must be identified and resisted as abuses of a biopolitical power that threatens individual decision-making at the end of life.

Part I

A. The birth of biopolitics

In the mid-1970s, while teaching at the Collège de France and writing in *The History of Sexuality*, Michel Foucault introduced the concept of biopower. Foucault argued that biopower “brought life and its mechanisms into the realm of explicit calculations and made knowledge-power an agent of the transformation of human life.”¹⁷ This transformation of human life resulted in the capitalistic modern state, which Foucault insisted was made possible by pre-existing institutional mechanisms and disciplinary technologies of biopower, i.e., “the controlled insertion of bodies into the machinery of production and the adjustment of the phenomena of population to economic processes.”¹⁸ The rise of contemporary Western society, therefore, was fueled by the development of this biopower phenomenon; a phenomenon that Foucault describes as the rise of state power over all “living things”—the power to regulate, discipline and take control of life and life processes. In contrast to the classical sovereign’s “right to take life or let live,” the modern state now wields a more expansive “right to make live or to let die.”¹⁹

According to Foucault, the era of biopower emerged during the eighteenth century as a result of the explosion of various disciplines and regulatory regimes designed to

¹⁷ MICHEL FOUCAULT, *THE HISTORY OF SEXUALITY, VOLUME 1: AN INTRODUCTION* [SEXUALITY] 143 (Robert Hurley, trans., Vintage Books 1978). For a helpful discussion of biopower and biopolitics, see Paul Rabinow, *Introduction*, in *THE FOUCAULT READER* 3, 12-23 (Paul Rabinow, ed., Pantheon Books, 1984).

¹⁸ FOUCAULT, *SEXUALITY*, at 140-41.

¹⁹ FOUCAULT, *SEXUALITY*, at 136. See also FOUCAULT, *LECTURES*, at 241. The sovereign’s right to take life and let live is symbolized by the sword. The state’s right to make live or let die is expressed, most frequently, in far more complex and complicated bureaucratic regulatory schemes.

subjugate individual bodies and to control burgeoning populations. Thus, the state's exercise of control and power over life and death operated along two trajectories, taking the forms of anatomo-politics (of the human body) and bio-politics (of the population).²⁰ In Foucault's account, anatomopolitics centered on the individual body as a machine to be disciplined, trained, optimized and integrated into efficient systems of economic control and state sustainability.²¹ Biopolitics, on the other hand, referred to the state's regulatory control over the population as a whole—the “species body, the body imbued with the mechanics of life and serving as the basis of the biological processes,” i.e., the ratio of births to deaths, the rate of reproduction, the fertility of the population, the level of health, and life expectancy and longevity.²² Thus as armies, schools, prisons, hospitals and workshops rapidly developed, so too did attendant “problems of birth rate, longevity, public health, housing, and migration,” and the subject of the state's mechanisms and calculations of power, increasingly, became the life (and death) of its citizenry, not as specific individuals, but as a population.²³

Foucault claimed that “[b]iopolitics deals with the population, with the population as political problem, as a problem that is at once scientific and political, as a biological

²⁰ FOUCAULT, SEXUALITY, at 139.

²¹ See generally Michel Foucault, *The Political Technology of Individuals*, in TECHNOLOGIES OF THE SELF: A SEMINAR WITH MICHEL FOUCAULT 152 (Luther H. Martin, et al. eds., Univ. of Mass. Press 1988) ([G]overnment has to worry about [individual citizens] only insofar as they are somehow relevant for the reinforcement of the state's strength: what they do, their life, their death, their activity, their individual behavior, their work, and so on . . . [S]ometimes what [the citizen] has to do for the state is to live, to work, to produce, to consume; and sometimes what he has to do is to die.”).

²² FOUCAULT, SEXUALITY, at 139. See also FOUCAULT, LECTURES, at 243.

²³ FOUCAULT, SEXUALITY, at 140. See generally GIORGIO AGAMBEN, HOMO SACER: SOVEREIGN POWER AND BARE LIFE [“HOMO SACER”] 119-135 (Daniel Heller-Roazen trans., Stanford Univ. Press 1998). Agamben notes that the integration of medicine and politics is one of the essential characteristics of modern biopolitics. This integration can be observed most clearly in the physicians Karl Brand and Viktor Brack, who were sentenced to death at Nuremberg for their complicity in the Nazi euthanasia program. *Id.* at 143. “[I]n the biopolitical horizon that characterizes modernity, the physician and the scientist move in the no-man's-land into which at one point the sovereign alone could penetrate.” *Id.* at 159.

problem and as power's problem."²⁴ Furthermore, with "the emergence of this technology of power over 'the' population as such, over men insofar as they are living beings . . . we have the emergence of a power that [Foucault called] the power of regularization."²⁵ Therefore, biopolitics as developed by Foucault is a political power of regulation and control that intervenes at a level of social generality where it can lower the mortality rate, raise life expectancy and stimulate the birth rate throughout the population at large.²⁶

The harnessing and exercising of this biopower, however, requires continuous regulatory and administrative mechanisms, and, thus, creates a political tension that is inextricably woven into the fabric of modern, liberal democratic societies and the administrative apparatus that supports them.²⁷ "And most important of all, regulatory mechanisms must be established to establish an equilibrium, maintain an average, establish a sort of homeostasis, and compensate for variations within this general population and its aleatory field."²⁸ The state's exercise of biopower to compel conformity and its tendency to oppress and to alienate results in political struggles and strategies that manifest in culture wars over one's "right" to life (and to death), to health, to happiness, to one's body, and "to rediscover what one is and all that one can be."²⁹

²⁴ FOUCAULT, LECTURES, at 245.

²⁵ FOUCAULT, LECTURES, at 247.

²⁶ FOUCAULT, LECTURES, at 244.

²⁷ Indeed, as Foucault notes, "[f]or millennia, man remained what he was for Aristotle: a living animal with the additional capacity for political existence; modern man is an animal whose politics calls his existence as a living being into question." FOUCAULT, SEXUALITY, at 143.

²⁸ FOUCAULT, LECTURES, at 246.

²⁹ FOUCAULT, SEXUALITY, at 145. At this point, Foucault leaves his background discussion of bio-power and bio-politics, and moves forward with his discussion of sex as a political issue. It is worth mentioning that he also includes in his litany the right "to rediscover what one is and all that one can be." *Id.* For an extended reflection on what it means to rediscover what one is and all that one can be, i.e., the experience of self-fulfillment, in the context of contemporary social, political, and legal attitudes towards sex, see Edward L. Rubin, *Sex, Politics, and Morality*, 47 WM AND MARY L. REV. 1, 13-34 (2005).

Alas, as the American experiment enters the 21st century, we see increasing debate about what constitutes the optimized state of life. Some of that debate, the portion relevant to artificial nutrition and hydration, will be addressed later in this paper. Indeed, we see increasing attempts by the state to control the biological beginnings and endings of life, even as individuals attempt to assert claims to autonomy and rights to self-determination. Thus, bioethics inevitably births biopolitics, as contemporary issues of life and death trigger power dynamics between individuals, an administratively-bureaucratized state, and a conservative ideological movement which seeks to regulate the culture via legislation advancing its version of the common good.³⁰

B. Biopolitical theory applied

Since its introduction in the mid-1970s, the concept of biopower and biopolitics has been developed and advanced by several theorists across an array of disciplines. Following Foucault, scholars have expanded the utility of these concepts by applying them to both macro and micro bioethical issues of our day. Before moving to our examination of post-*Schiavo* feeding tube legislation and the notion of proxy wars, it may be helpful to spend a few moments briefly considering the diversity of applications and analyses offered by biopolitical theory.

1. Reproduction

Anthropologist Paul Rabinow and sociologist Nikolas Rose describe “biopower” as “rationalized attempts to intervene upon the vital characteristics of human existence.”³¹ More precisely, they define “biopolitics” as “all the specific strategies and contestations

³⁰ I say much more about this conservative ideological movement, i.e., the Religious Right, and the phenomena of *Biblical BioPolitics* in Joshua E. Perry, *Biblical BioPolitics: Judicial Process, Religious Rhetoric, Terri Schiavo and Beyond* [Biblical BioPolitics], 16 HEALTH MATRIX 2:553-650 (2006).

³¹ Paul Rabinow & Nikolas Rose, *Biopower Today*, 1 BIOSOCIETIES 195-217, 197 (2006).

over problematizations of collective human vitality, morbidity and mortality; over the forms of knowledge, regimes of authority and practices of intervention that are desirable, legitimate and efficacious.”³² As with Foucault, biopolitics as formulated by these scholars becomes an analytical concept with considerable critical force.³³ In their most recent article, Profs. Rabinow and Rose focus upon reproduction as “a problem space, in which an array of connections appear between the individual and the collective, the technological and the political, the legal and the ethical.”³⁴ As an aid to our understanding of biopolitics as a concept, we will briefly review their discussion of this “biopolitical space par excellence.”³⁵

Rabinow and Rose note that current public policy determinations are marked by “new modes of individualization and conceptions of autonomy with their associated rights to health, life, liberty and the pursuit of a form of happiness.”³⁶ For instance, new reproductive technologies, including in vitro fertilization and pre-implantation genetic diagnosis, harmonize well with both “the rhetoric of choice” and “the ethic of autonomy.”³⁷ However, Rabinow and Rose argue that these developments are limited in their impact upon the population at large because their use is neither routine nor guaranteed to succeed. For instance, the authors note that reproductive choice in the form of embryo selection “has been almost entirely limited to the identification of fetuses with

³² Rabinow & Rose, *Biopower Today*, at 197.

³³ Profs. Rabinow and Rose argue that biopolitics must be grounded in historical or genealogical analysis, as opposed to a meta- or trans-historical theory that might attempt to “describe everything but analyse nothing.” Rabinow & Rose, *Biopower Today*, at 199.

³⁴ Rabinow & Rose, *Biopower Today*, at 208. In addition to issues related to reproduction, Profs. Rabinow and Rose also discuss race and genomic medicine in this article. *Id.* at 205ff, 212ff.

³⁵ Rabinow & Rose, *Biopower Today*, at 208.

³⁶ Rabinow & Rose, *Biopower Today*, at 204.

³⁷ Rabinow & Rose, *Biopower Today*, at 208.

major malformations or crippling and terminal genetic disorders”—not the eugenically-inspired “improvement of the biological stock of the population.”³⁸

At the more macro level, however, contemporary biopolitical strategies can be observed in the management of reproduction in the form of campaigns throughout Asia and Latin America to limit population growth.³⁹ On this point, Rabinow and Rose highlight China’s One Child Policy and various sterilization campaigns around the world. Noting the controversial nature of these policies, the authors again stress the distinction between limiting population in the interests of national economic prosperity and the eugenic “purification of the race by elimination of degenerates.”⁴⁰ In a less repugnant category, state-sanctioned policies to reduce “the levels of inherited morbidity and pathology in a population” are often sanctioned by religious and secular authorities and approved by the population.⁴¹ Examples of this more acceptable impact on the “individual reproductive choices of each citizen” include systematic and nationwide testing to identify and control the genetic dissemination of cystic fibrosis or Tay Sachs.⁴²

The authors’ point in discussing reproduction as a biopolitical issue is to highlight the idea that genetic testing and population controls are not necessarily leading us down the road to eugenics or genocide. On the contrary, they assert that the thrust of “contemporary biopolitics in the realm of reproduction” is geared more towards vitality—not mortality.⁴³ Thus, these authors caution against leaping to unwarranted

³⁸ Rabinow & Rose, *Biopower Today*, at 208, 210. Although only recently published, the authors were originally writing in August 2003. Since then, developments suggest that selection along other criteria is not too far in the future, and fears concerning slippery slopes may not be completely unfounded. See Beezy Marsh, “Designer Baby” Clinic to Charge £6,000 Per Child, NEWS TELEGRAPH (U.K.), Mar. 26, 2006.

³⁹ Rabinow & Rose, *Biopower Today*, at 209.

⁴⁰ Rabinow & Rose, *Biopower Today*, at 210.

⁴¹ Rabinow & Rose, *Biopower Today*, at 210.

⁴² Rabinow & Rose, *Biopower Today*, at 210.

⁴³ Indeed, “letting die is not making die.” Rabinow & Rose, *Biopower Today*, at 211 (emphasis in original).

conclusions that recall past atrocities and unnecessarily raise latent fears and anxieties—particularly among vulnerable populations.⁴⁴ While a comprehensive review of the authors’ complete argument is not relevant to the purpose of this paper, we can quickly surmise from this brief review that social and political governance of life, death, and technologies are constitutive elements of the contemporary biopolitics.

2. Palliative Care, Death & Dying

Of particular value to our discussion is a recent contribution to the literature from legal scholar John Parry, who has applied a biopolitical analysis to constitutional law and the use of governmental power to regulate pain and to manage death.⁴⁵ Parry’s work in this area focuses primarily on the Supreme Court’s opinion in *Gonzales v. Raich*.⁴⁶ The facts in the *Gonzales* case are not complex. In 1996 California passed the Compassionate Use Act creating a system by which “seriously ill” California residents (and their primary caregiver) could legally possess or cultivate marijuana for medicinal purposes with the

⁴⁴ In Part II, I discuss the National Right to Life Committee’s Model Act, which, I would suggest, intentionally uses the misleading and alarming title: “The Starvation and Dehydration of Persons with Disabilities Prevention Act.” For additional analysis on the use of rhetoric as a biopolitical strategy, see Perry, *Biblical BioPolitics*. Ruth Macklin has also noted the use by some bioethical commentators of “metaphors and slogans as substitutes for empirical evidence and reasoned arguments; patently offensive analogies; [and] deliberately misleading terminology.” *The New Conservatives in Bioethics: Who Are They and What Do They Seek?* 36 HASTINGS CENTER REPORT 1:34, 38 (Jan. – Feb. 2006).

⁴⁵ John T. Parry, “*Society Must Be [Regulated]*”: *Biopolitics and the Commerce Clause in Gonzalez v. Raich* [“*Society*”], 9 LEWIS & CLARK L. REV. 853, 863-77 (2005). Professor Parry is one of the few American legal scholars who has addressed the notion of biopolitics. A sampling of others scholars in the legal academy or publishing in the law literature who have written recently on biopolitics or biopower include: Peter Fitzpatrick, *Homo Sacer and the Insistence of Law*, in *POLITICS, METAPHYSICS, AND DEATH: ESSAYS ON GIORGIO AGAMBEN’S HOMO SACER [POLITICS, METAPHYSICS, & DEATH]* (Andrew Norris ed., Duke University Press 2005); Adam Thurschwell, *Cutting the Branches for Akiba: Agamben’s Critique of Derrida in POLITICS, METAPHYSICS, & DEATH*; Craig Willse & Dean Spade, *Freedom in a Regulatory State?: Lawrence, Marriage and Biopolitics*, 11 WIDENER L. REV. 309 (2005); Austin Sarat & Nassar Hussain, *On Lawful Lawlessness: George Ryan, Executive Clemency, and the Rhetoric of Sparing Life*, 56 STAN. L. REV. 1307 (2004); Mariella Pandolfi, *Contract of Mutual (In)Difference: Governance and the Humanitarian Apparatus in Contemporary Albania and Kosovo*, 10 IND. J. GLOBAL LEG. STUD. 369 (2003); Adam Thurschwell, *Specters of Nietzsche: Potential Futures for the Concept of the Political in Agamben and Derrida*, 24 CARDOZO L. REV. 1193 (2003); and Eugene MacNamee, *The Government of the Tongue*, 14 CARDOZO STUD. L. & LIT. 427 (2002).

⁴⁶ 125 S. Ct. 2195 (2005).

approval or recommendation of a physician.⁴⁷ Angel Raich and Diane Monson, California residents suffering from a variety of serious health afflictions, relied heavily on daily cannabis treatments in order to function.⁴⁸ They were both under the care and supervision of licensed, board-certified family practitioners, who were convinced that marijuana was the only drug available that could provide effective treatment.⁴⁹ In August 2002 federal Drug Enforcement Agency (DEA)—pursuant to the federal Controlled Substances Act—came to Monson’s home, where they seized and destroyed all six of her cannabis plants.⁵⁰

When the case reached the Supreme Court it was framed as a question of whether Congress’ power to regulate interstate markets for medicinal substances includes markets that are supplied with drugs that are locally grown and consumed.⁵¹ The Court, in a 6-3 decision, held that Congress does have the power to regulate purely local activities that are part of an economic class of activities, i.e., the production, cultivation, distribution, possession, or consumption of a commodity that may have a substantial effect on interstate commerce or the regulation of interstate commerce. The scope of this federal regulatory authority, according to the Court, reaches even those who use homegrown medicinal marijuana in accordance with the laws of their state.

While on the surface the *Raich* case raises complicated questions of federalism, Professor Parry instead concentrates his focus on the deeper currents of the Court’s jurisprudence, namely the “broad idea and endorsement of comprehensive regulatory power, be it federal (through the Commerce Clause) or state (through the so-called police

⁴⁷ CAL. HEALTH & SAFETY CODE ANN. §§ 11362.5-11362.9 (West Supp. 2006).

⁴⁸ See *Raich*, 125 S. Ct. at 2199-2200.

⁴⁹ See *Raich*, 125 S. Ct. at 2200.

⁵⁰ See *Raich*, 125 S. Ct. at 2200. See also Controlled Substances Act, 21 U.S.C. § 801 *et seq.*

⁵¹ See *Raich*, 125 S. Ct. at 2201.

power).”⁵² Parry notes that “at least eight of the justices agreed in *Raich* on the constitutional principle that one of the proper concerns of government is to regulate aggregate public health, which in turn means controlling the individual bodies of citizens as units of the larger public.”⁵³ It is this aspect of *Raich*—“its easy approval of comprehensive and pervasive biopolitical regulation”—that triggers Parry’s ominous comment regarding the grave implications of this regulatory action:

[T]he issue in *Raich* was the provision of marijuana to seriously ill people for the purpose of alleviating their pain. The power “to make live and let die” is neither a metaphor nor a theoretical frolic. Biopolitical regulation of populations is concrete—individuals will live or die or will suffer more or less pain as a result of it.⁵⁴

Parry’s discussion of *Raich*, like the Court’s opinion, does not address the substantive questions swirling around the legitimacy of medicinal marijuana and the boundaries of appropriate pain management and palliative care. Rather, Parry’s focus is on the reality of biopolitical regulation in the modern administrative state and the challenge this presents to individual interests.

For illustrative purposes, Parry also includes a brief discussion of the right to obtain an abortion—“a medical procedure every aspect of which is heavily regulated.”⁵⁵ A woman seeking to exercise her right to terminate her pregnancy must navigate through an elaborate series of regulatory hurdles each allegedly premised on the state’s interest in protecting her health. Paradoxically, however, a woman desiring to assert her legal right to control her body is not freed from the confines of the regulatory state; she is only

⁵² Parry, “*Society*”, at 863.

⁵³ Parry, “*Society*”, at 868.

⁵⁴ Parry, “*Society*”, at 868.

⁵⁵ Parry, “*Society*”, at 871.

enmeshed in it all the more.⁵⁶ Parry grants that some manner of regulation is in the best interest of the woman's health. Yet, the politicized nature of much of the regulation, i.e., the required reading material discussing fetal development, is, for many, a more problematic ideologically-driven expression of biopolitics.

Parry's final application of biopolitical theory focuses on the regulation of end of life decisions. In a comment that triggers images of Karen Quinlan, Nancy Cruzan, and Terri Schiavo, Parry remarks:

Death is no longer something that just happens. Rather it is a process, planned in advance and monitored and controlled by lawyers, doctors, family members, legislatures, government officials, and the person who is dying. It is the concern, in short, of biopolitics.⁵⁷

As this quote suggests, biopolitics highlights the strategic relationships between government actors, the affected individuals in the population, and participants in the political economy.⁵⁸ Indeed, during the latter half of the twentieth century, a range of powerful regulatory agencies, transnational bodies, bioethics commissions, and professional organizations emerged to create a type of "bioethical complex."⁵⁹ Moreover, "the increasing medicalization, bureaucratizing, and politicization of death" creates predictable conflicts as individuals suffer encroachments upon their body, their life, and their death.⁶⁰ Sure, "[i]ndividuals can make their own choices through such things as living wills, but preparing, recognizing, and implementing a living will are not

⁵⁶ Parry, "Society", at 872.

⁵⁷ Parry, "Society", at 873.

⁵⁸ See Maurizio Lazzarato, *From Biopower to Biopolitics*, 13 THE WARWICK JOURNAL OF PHILOSOPHY 100-111 (2002) (Ivan A. Ramirez, trans.) ("The fundamental political problem of modernity is not that of a single source of sovereign power, but that of a multitude of forces that act and react amongst each other according to relations of command and obedience."). Lazzarato illustrates his point by noting that relations between the sexes, student and teacher, patient and doctor, employee and employer are all "relations between forces that always involve a power relation." *Id.* at 104.

⁵⁹ Rabinow & Rose, *Biopower Today*, at 203.

⁶⁰ Parry, "Society", at 873.

exceptions to state control. Rather, they are processes that are approved and regulated by the state for our benefit.”⁶¹ Thus, similar to abortion, an individual’s desires regarding what should or should not happen to her body are, in our biopolitical age, increasingly subject to the highly political processes of state regulation, including the ideological influence of special interest organizations.

These processes, regrettably, were most recently on parade during the Terri Schiavo saga⁶²—an event that presented a wavering indeterminacy of death “in a shadowy zone beyond coma” and “an analogous oscillation between medicine and law, medical decision and legal decision.”⁶³ In the *Schiavo* case, we witnessed a political and legal fight over the biological body of Terri Schiavo—a body that had, in fact, “entered a zone of indeterminacy in which the words ‘life’ and ‘death’ had lost their meaning.”⁶⁴ At stake in this biopolitical conflict was Mrs. Schiavo’s sovereignty over her own existence. Her life (and death) became politicized as her husband attempted to exercise her right to refuse artificial nutrition and hydration (ANH). Her husband’s attempts, however, only served to legitimate the biopolitical boundaries of state action, as Agamben explains: “[T]he rights won by individuals in their conflicts with central powers always simultaneously prepared a tacit but increasing inscription of individuals’ lives within the state order, thus offering a new and more dreadful foundation for the very sovereign power from which they wanted to liberate themselves.”⁶⁵ Thus, as Parry notes, rights serve both to distinguish us from those outside the political community while

⁶¹ Parry, “*Society*”, at 873.

⁶² For a detailed account of the *Schiavo* saga, see Parry, *Biblical BioPolitics*.

⁶³ GIORGIO AGAMBEN, *HOMO SACER: SOVEREIGN POWER AND BARE LIFE* [“HOMO SACER”] 163 (Daniel Heller-Roazen trans., Stanford Univ. Press 1998) (describing Karen Quinlan).

⁶⁴ AGAMBEN, *HOMO SACER*, at 164 (describing Karen Quinlan’s body).

⁶⁵ AGAMBEN, *HOMO SACER*, at 121.

simultaneously marking us as members of a regulated community.⁶⁶ “In this sense, rights are part of biopolitics—or, rather, rights discourse and biopolitics are both aspects of what it means to live [and die] in a modern society.”⁶⁷

So Terri Schiavo’s life and death present us with a thoroughly modern continuum. Without heroic medical interventions and continuing ANH via a surgically implanted feeding tube, Mrs. Schiavo’s body would have ceased functioning long before the final court order which ended the saga that had begun fifteen years earlier with Mrs. Schiavo’s still-unexplained collapse. As Foucault notes, “we have become so good at keeping people alive that we’ve succeeded in keeping them alive when, in biological terms, they should have been dead long ago.”⁶⁸ Indeed, Mrs. Schiavo was sustained for fifteen years by a medico-juridico-political power that intervened to make her live for many years and, ultimately, at the end, managed her death.⁶⁹

During those fifteen years her life was reduced to biological life—“anatomy in motion”—“death in motion,” a set of functions whose purpose was “no longer the life of an organism.”⁷⁰ Maintained only with the assistance of life-support technology, Mrs.

⁶⁶ Parry, “*Society*”, at 872. See also AGAMBEN, *HOMO SACER*, at 131 (“One of the essential characteristics of modern biopolitics . . . is its constant need to redefine the threshold in life that distinguishes and separates what is inside from what is outside. . . . And when natural life is wholly included in the *polis* . . . these thresholds pass . . . beyond the dark boundaries separating life from death in order to identify a new living dead man, a new sacred man.”).

⁶⁷ Parry, “*Society*”, at 872.

⁶⁸ FOUCAULT, *LECTURES*, at 244.

⁶⁹ Professor Parry explains:

However one chooses to characterize the Schiavo controversy, it is clear that there was nothing “natural” about it. After her injury, she could only exist—and could only die—within a matrix of pervasive and invasive legal and medical regulation. Indeed, to die, she would have to be killed, if only in the sense that medical professionals would take deliberate actions with the knowledge that those actions would lead to (and arguably “cause”) her death. . . . With the Schiavo case, and by implication with the thousands or more of managed deaths that take place every year, there was no baseline outside biopolitics, no way for “nature to take its course.”

Parry, “*Society*”, at 874-75.

⁷⁰ AGAMBEN, *HOMO SACER*, at 186 (“[S]ince life and death are now merely biological concepts, as we have seen, Karen Quinlan’s body—which wavers between life and death according the progress of medicine and

Schiavo's life was sustained by virtue of legal decisions.⁷¹ Indeed, the Schiavo saga demonstrated that “we are not only, in Foucault's words, animals whose life as living beings is at issue in their politics, but also—inversely—citizens whose very politics is at issue in their natural body.”⁷²

Part II. Post-Schiavo ANH legislation

In October 2003, following Florida's passage of Terri's Law, the legislation granting Governor Jeb Bush the unilateral power to re-insert Mrs. Schiavo's feeding tube, the National Right to Life Committee (NRLC) published a model “Starvation and Dehydration of Persons with Disabilities Prevention Act” (the Model Act) and called for its adoption in all fifty states.⁷³ With the exception of Florida, states were slow to answer the NRLC's call.⁷⁴ Approximately fifteen months later, however, as the Terri Schiavo

the changes in legal decisions—is a legal being as much as it is a biological being. A law that seeks to decide on life is embodied in a life that coincides with death.”).

⁷¹ AGAMBEN, *HOMO SACER*, at 186.

⁷² AGAMBEN, *HOMO SACER*, at 188. See generally Andrew Norris, *Introduction: Giorgio Agamben and the Politics of the Living Dead*, in *POLITICS, METAPHYSICS, AND DEATH: ESSAYS ON GIORGIO AGAMBEN'S HOMO SACER [POLITICS, METAPHYSICS, & DEATH] 2* (Andrew Norris ed., Duke University Press 2005) (“For millennia, man remained what he was for Aristotle: a living animal with the additional capacity for political existence; modern man is an animal whose politics calls his existence as a living being into question.” FOUCAULT, *SEXUALITY*, at 143). See also AGAMBEN, *HOMO SACER*, at 4 (“[T]he entry of *zoē* into the sphere of the *polis*—the politicization of bare life as such—constitutes the decisive event of modernity and signals a radical transformation of the political-philosophical categories of classical thought.”).

⁷³ Wes Allison, *New Life for the Right-to-Life Movement*, *ST. PETERSBURG TIMES (FLORIDA)*, Oct. 25, 2003, at A1. The NRLC's executive director explained: “We must not let the horror and outrage over the attempted starvation and dehydration of Terri Schindler-Schiavo dwindle and die away before we have acted to secure protection for the thousands facing a similar fate.” Press Release, National Right to Life, Spurred By Schindler-Schiavo Case, Model State Law to Prevent Starvation and Dehydration Proposed (Oct. 2003) (on file with author).

⁷⁴ On November 21, 2003, Florida became the first state to consider this model legislation. See S.B. 692, 2004 Leg., 106th Sess. (Fl. 2004). However, on January 14, 2004, the model legislation was introduced in Georgia. See H.B. 1132, 2003-04 Gen. Assem., 147th Sess. (Ga. 2004). Less than two weeks later, similar, although not identical, legislation was introduced in South Dakota. See S.B. 187, 2004 Leg., 79th Sess. (S.D. 2004).

case began to capture the nation’s attention, a wave of Schiavo-inspired legislation began to form, guided by the NRLC and its local state affiliates.⁷⁵

By January 2005, as media attention surrounding the *Schiavo* case intensified, state legislators started to take notice, and by June 2006, fifty-five bills or resolutions had been filed in twenty-four different states.⁷⁶ The vast majority (if not all) of this legislation was introduced in reaction to Mrs. Schiavo’s tragedy. Consider the following comments from sponsoring legislators:

“This bill is a direct result of the Terry [sic] Schiavo case. Ms. Schiavo was starved and dehydrated to death under extremely dubious circumstances. It was a travesty of justice . . . that she should literally be ‘put to death.’”—John E. Rooney, New Jersey State Assemblyman⁷⁷

“The reason for proposing this legislation was in the wake of Terry [sic] Schiavo dying from lack of hydration and nutrition. . . . The intent of this legislation is that if a family is in disagreement . . . then the decision will be to err on the side of life.”—John Stahl, Michigan State Representative⁷⁸

“After the Terri Schiavo tragedy, [I discovered] that New York State does not have any laws to protect human rights in instances such as the Schiavo case. That was the purpose in proposing these two pieces of legislation:

⁷⁵ Additionally, disability advocates, including most notably Not Dead Yet, have also been prominent and vocal supporters of much post-*Schiavo* legislation. Their activism on this issue, however, is beyond the scope of this paper.

⁷⁶ The twenty-four states include Alabama, Arizona, California, Colorado, Florida, Georgia, Hawaii, Iowa, Kansas, Kentucky, Louisiana, Michigan, Minnesota, Mississippi, Missouri, New Jersey, New York, North Carolina, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, and Wisconsin. For a listing of bill numbers and a detailed description of the legislation, see the thorough research of Elena N. Cohen and Theresa Connor, assisted by Kathy Cerminara and Kathryn Tucker, prepared for MergerWatch as a “Summary of State Bills Restricting End-of-Life Choices Introduced in 2005 and 2006” available at http://www.mergerwatch.org/press_releases.html. This extremely helpful research was current as of February 2006. Not reflected in this data are the following bills that were introduced between February and June 2006: Alabama SB493; California SB1280; Georgia SR1067; Oklahoma SB1624; and, Tennessee HB2726, SB2749. The MergerWatch Project is a nonprofit organization “committed to fighting the spread of faith-based policies and restrictions in the American health system.” See “Mission” available at www.mergerwatch.org.

⁷⁷ E-mail from John E. Rooney, Assemblyman, New Jersey Legislative District 39, to Joshua E. Perry (June 9, 2006) (on file with author). Assemblyman Rooney was responding to an inquiry about why he proposed Assembly Bill 2117, “The Starvation and Dehydration of Persons With Disabilities Prevention Act.”

⁷⁸ E-mail from John Stahl, Representative, Michigan Legislative District 82, to Joshua E. Perry (June 12, 2006) (on file with author). Representative Stahl was responding to an inquiry about why proposed House Bill 4743, a bill that would prohibit the withholding or withdrawal of nutrition or hydration under certain circumstances.

to protect human rights and avoid the tragic outcome that befell Terri Schiavo.”—Daniel L. Hooker, New York State Assemblyman⁷⁹

“Senator Morrow authored this legislation to prevent what happened to Terri Schiavo here in California. . . . [I]f a person has not clearly expressed their wishes for a particular circumstance, the state and the person’s protectors should err on the side of life and give them basic rights: foods and fluids. . . . [Otherwise,] it becomes essentially starving/dehydrating a person to death, rather than simply ‘allowing’ someone’s illness to take its natural course. . . . [Neither] the State, nor any of its citizens, has the right to kill someone that way.”—Amanda Morgan, Office of Bill Morrow, California State Senator⁸⁰

Twenty-three of the fifty-five bills are based directly on a version of the NRLC’s Model Act and are being proposed and actively supported by affiliated state Right to Life organizations, Americans United For Life, and other groups whose primary long-standing commitment has centered on criminalizing abortion.⁸¹

⁷⁹ Letter from Daniel L. Hooker, Assemblyman, New York Legislative District 127, to Joshua E. Perry (June 8, 2006) (on file with author). Assemblyman Hooker was responding to an inquiry about why he proposed Assembly Bills 7911 and 7912, bills that, respectively, would require a jury trial if the surrogate decision maker advocated on behalf of an outcome “intended to result in the death” of the patient and would create a presumption that a patient would desire ANH if necessary to sustain life. *Accord* letter from Serphin R. Maltese, Senator, New York Queens County, to Joshua E. Perry (June 19, 2006) (on file with author) (“This bill [S.4083] was introduced as a reaction to the controversy surrounding the death of Ms. Terri Schiavo. . . . Providing food and water to a patient is part of the basic care of a patient and by no means should be defined as an extraordinary measure to extend a life. Ordinary daily use of feeding tubes is basic care that does not require medical supervision. Death by starvation and dehydration is a long grueling process. Before a patient is subjected to such a death there should be no doubt as to the patient’s wishes regarding the provision of artificial nutrition and hydration.”). *See also* Maya Bell, *Debate About How We Die Rages On, But Chasm Grows*, ORLANDO SENTINEL (Mar. 26, 2006) (quoting Margie Montgomery, executive director of the Kentucky Right to Life Association: “The Supreme Court was wrong when it ruled in the Dred Scott decision that black people were not legally people . . . and they were wrong in *Cruzan*. Food and water is not medical treatment. It is basic care. You don’t starve a dog to death, much less a human being.”).

⁸⁰ E-mail from Amanda Morgan, Office of Senator Bill Morrow, California Senate District 38, to Joshua E. Perry (June 13, 2006) (on file with author). Ms. Morgan was responding to an inquiry about why Senator Morrow proposed Senate Bill 1280, “The Starvation and Dehydration of Persons With Disabilities Prevention Act.”

⁸¹ For instance, in California, Senator Morrow’s legislation is being pushed by the following groups, *inter alia*: Americans United for Life; California Pro-Life Council; Concerned Women for America; and the Terri Schindler-Schiavo Foundation, Center for Healthcare Ethics. *See* e-mail from Amanda Morgan, Office of Senator Bill Morrow, California Senate District 38, to Joshua E. Perry (June 13, 2006) (on file with author). *Accord* e-mail from Dwayne Alons, Representative, Iowa House District 4, to Joshua E. Perry (July 2, 2006) (on file with author) (“The groups supporting HSB 302 would be the National Right to Life and other pro-life groups.”) Representative Alons was responding to an inquiry about why he proposed HSB 302, “The Iowa Starvation and Dehydration of Persons With Disabilities Prevention Act.”

The NRLC Model Act creates a presumption that every person incompetent to make decisions affecting medical treatment desires artificial nutrition and hydration (ANH) “to a degree that is sufficient to sustain life.”⁸² In a dramatic shift from settled legal precedent and most state statutes, the Model Act would prevent the patient’s guardian, surrogate, or any other person, as well as any agency or court, from making a decision to withhold or withdraw ANH except in two narrow circumstances.⁸³ First, the presumption is in applicable if ANH would not contribute to the sustenance of the patient’s life or the provision of comfort.⁸⁴ In other words, if ANH will not prolong the patient’s biological life or provide palliation, it can be discontinued. The second circumstance in which the presumption does not apply is if the patient has executed an advance directive specifically authorizing the withholding or withdrawal of ANH, “*to the extent the authorization applies.*”⁸⁵ For enforcement, the Model Act creates a cause of action for injunctive relief to stop withdrawal of ANH in violation of the Model Act’s provisions or to initiate legal proceedings to determine whether there is clear and convincing evidence of express and informed consent to withdrawal of ANH “*in the applicable circumstances.*”⁸⁶

I emphasize the terms “to the extent authorization applies” and “in the applicable circumstances” for two reasons. First, it should be noted that these patently ambiguous phrases could easily become silly putty in the hands of a crafty and creative lawyer. If

⁸² NRLC Model Starvation and Dehydration of Persons With Disabilities Prevention Act (Revised January 2006) [NRLC Model Act] § 3(A) (on file with author and *available at* www.nrlc.org).

⁸³ NRLC Model Act § 3(B) (on file with author). My analysis of the Model Act is limited to the revised version current as of January 2006. The original version introduced in October 2003 was the basis for much of the NRLC-derived legislation introduced prior to January 2006. Detailed discussion of the earlier version can be found in JON B. EISENBERG, USING TERRI: THE RELIGIOUS RIGHT’S CONSPIRACY TO TAKE AWAY OUR RIGHTS 219-225 (2005).

⁸⁴ NRLC Model Act § 4(A) (on file with author).

⁸⁵ NRLC Model Act § 4(B) (emphasis added) (on file with author).

⁸⁶ NRLC Model Act § 5(A) (emphasis added) (on file with author).

any of the enumerated persons with standing⁸⁷ object to the withdrawal of ANH, all they must do is secure a lawyer who is willing to argue that in the particular and precise circumstances at hand, the authorization set forth in the advanced directive does not apply. Considering the infinite variety of circumstances in which a patient might become incapacitated and reliant upon ANH, it would be impossible for an advanced directive to be drafted in such a way as to prevent a legal challenge. Moreover the legislation elevates the importance of the written advance directive—a document that only a small percentage of the population has executed⁸⁸—to a degree that even oral testimony by the patient’s surrogate relating conversations with the patient or detailed descriptions of the patient’s life experiences would probably fail to meet the clear and convincing evidentiary standard demanded by the Model Act.

The second reason we must pause and contemplate the italicized phrases are because they highlight an important biopolitical dynamic between the sovereign (or the one in power) and the notion of legal exception.⁸⁹ Quoting Carl Schmitt at length, Agamben notes that “[t]he exception explains the general and itself. And when one really wants to study the general, one need only look around for a real exception. It brings everything to light more clearly than the general itself.”⁹⁰ In the juridico-political

⁸⁷ Legal action may be brought by: the patient’s spouse, parent, child or sibling; the patient’s current or former health care provider; the patient’s legally appointed guardian; a state protection or advocacy agency; or, a public official with appropriate jurisdiction to prosecute or enforce state law. *See* NRLC Model Act § 5(B)(a)-(e). Note that the Model Act does not rank or prioritize these parties. A state governor or agency director is granted the same power to bring legal action to block removal of a feeding tube as the patient’s spouse, parent, or children.

⁸⁸ The most recent survey reveals that a mere 29% of Americans have a living will. “More Americans Discussing and Planning End-of-Life Treatment.” The Pew Research Center for the People and The Press. Jan. 5, 2006.

⁸⁹ *See* Agamben for further discussion of Carl Schmitt and the notion that “the sovereign is he who decides on the state of exception.” *See* AGAMBEN, HOMO SACER, at 11, 15.

⁹⁰ AGAMBEN, HOMO SACER, at 16. *See also* Giorgio Agamben, *The State of Exception*, in POLITICS, METAPHYSICS, AND DEATH at 284ff. My use of “legal exception” differs from Agamben’s notion of the “state of exception” concept, which is best exemplified in those moments when the sovereign sets apart a

order, the legal exceptions mark the boundaries of individual freedom and state power. These exceptions are what trigger litigation. These exceptions are where the action and the power are located. The fact that the Model Act wraps the legal exceptions to its presumption in such ambiguous language as “*to the extent the authorization applies*” and “*in the applicable circumstances*” highlights the divestment of power from the individual and her surrogate to anyone who willing to assume and assert the power granted by the Model Act.

Indeed, as written, the NRLC Model Act empowers a relatively broad array of individuals and state actors to intervene in an incompetent patient’s end-of-life medical treatment and fight to continue ANH regardless of the incompetent patient’s desires—unless the patient is among that 29% of the country with an advanced written directive *and* the advanced directive is able to withstand the legal scrutiny invited by the italicized language of exception. Again, as set forth in the Model Act, operation of the exceptions to the presumption in favor of indefinitely continuing ANH will turn ultimately on the interpretation of the written language in the advanced directive and an analysis of the specific circumstances surrounding the patient’s incompetency. This invites an unacceptable degree of juridico-political intervention and control at the bedside of a patient who is confronting the end of her life.

Thus, for instance, if we consider the outcome of the *Schiavo* case, which prompted the NRLC to draft the Model Act and many of the elected officials throughout the U.S. to propose various bills that would restrict an incompetent patient’s freedom to discontinue ANH, it becomes clear that under the regime envisioned by the Model Act,

time and place where the very rule of law can be suspended in the (alleged) best interests of the nation, i.e., Nazi concentration camps and Guantanamo Bay.

Mrs. Schiavo would still be receiving ANH. She did not have an advanced directive, and despite recollections of her husband and other close friends and family members regarding her wishes and the entire arc of her life⁹¹, her situation would not qualify as an exception has designated by the Model Act. Thus, in Agamben's terms, the Model Act creates an environment in which biological life—maintained by the intervention of ANH—becomes completely divorced from the form of life that was Terri Schiavo.⁹²

In the absence of the Model Act, the current legal regime throughout most of the country respects the decision of a proxy made on behalf of the incapacitated patient. In most instances, the settled legal consensus respecting patient autonomy accommodates individual, personalized decision-making by a proxy that is consistent with the life lived and beliefs held by the patient before entering into the final silence of the persistent vegetative state. If specific statements or the totality of an incompetent patient's life can somehow establish a clear preference for indefinite continuation of treatment with artificial nutrition and hydration, I am willing to entertain the possibility that the law should afford such a patient the final liberty to pursue such a preference. Indeed, such is the breadth of options currently provided under the legal status quo. Regardless of what decision is desired—to continue ANH or to withdraw—the current flexibility of most state laws affords respect and dignity to the individual.

As threatened by the Model Act, however, the state's power to regulate and control the death and dying process⁹³ of all its incapacitated citizens would supersede the

⁹¹ See generally ROGER DWORKIN, LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA, AND INDIVIDUAL FREEDOM 216, 224 (1994) (defending the notion that individual autonomy must include the power to make "the most central, personality-defining judgments about their own lives for themselves" and to shape the overall kind of life the individual wants to have led and arguing against the imposition of collective judgment on "matters of the most profound spiritual character").

⁹² AGAMBEN, HOMO SACER, at 186.

⁹³ See discussion *infra* Part I(A).

potentially contrary desires of those patients who, perhaps because they are in a persistent vegetative state, would not desire continuing ANH. Such a scenario would allow biological life—the body⁹⁴—to become a (bio)political tool for the use of those seeking to advance biopolitical agenda of control across other medico-legal domains. It is to this wider consideration that we will now turn.

Part III. Proxy wars

Writing on the first anniversary of Terri Schiavo’s death, columnist Ellen Goodman noted that “since Schiavo’s death, conservative groups have filed 49 bills in 23 state legislatures seeking laws that would leave any patient without a living will—such as Terri—on life support.”⁹⁵ But then she noted that most of this proposed legislation was either dead, stalled, or watered down, which prompted her to muse rhetorically, “[W]hat if they gave a culture war and nobody came?”⁹⁶ In this third Part, I will argue that when viewed through the theoretical lens of biopolitics, the post-*Schiavo* legislation must be taken more seriously than Goodman’s dismissive culture war query suggests. Staying with the military metaphors and building upon Alta Charo’s insightful phraseology, I will argue that the post-*Schiavo* end-of-life legislation represents a proxy war in the ongoing cultural battles over the social frontiers of biologic, nonsentient human life.

Ultimately at stake in this biopolitical proxy war are the boundaries of government regulation and the limits of individual freedom. Here there is a tension. On this point, Professor Parry observes, “biopolitics simply reflects the enlightenment project

⁹⁴ “Like the concepts of sex and sexuality, the concept of the “body” too is always already caught in the deployment of power. The “body” is always already a biopolitical body . . .” AGAMBEN, *HOMO SACER*, at 187.

⁹⁵ Ellen Goodman, *Schiavo Debate is Back But Life’s Moved On*, THE BOSTON GLOBE, Mar. 31, 2006, at A15.

⁹⁶ Ellen Goodman, *Schiavo Debate is Back But Life’s Moved On*, THE BOSTON GLOBE, Mar. 31, 2006, at A15

of promoting reason . . . Social structures have become rationalized, so that governments are more likely to operate by articulated policy instead of fiat, the rule of law instead of whim, and democracy instead of hereditary rule or warlordism.”⁹⁷ Thus as rational, rights-bearing individuals go about crafting the public policies and rules of law—particularly with regard to issues of the body—the cultural battlefield emerges. Ideological fights erupt between competing understandings of complex concepts, such as human dignity, life’s sanctity, the common good, and the individual’s flourishing—even unto death. I suggest that the Terri Schiavo drama and the wave of legislative action that has been created in its wake must be seen in these biopolitical terms. Furthermore, regardless of the ultimate success of the Model Act and its progeny, viewing these legislative developments through the lens of biopolitics prevents us from merely shrugging-off these proposals as blips on the radar unworthy of our attention and analysis.

Kathryn Hinsch, founding director of the progressive Women’s Bioethics Project, understands the bigger picture represented by the proposed ANH laws. She has recently noted that “conservative religious groups have devoted substantial resources to affecting bioethics public policy.”⁹⁸ She argues:

⁹⁷ Parry, “*Society*”, at 877. But note that in his conclusion, Parry seems to be slightly more ambivalent than I on the question of whether the modern, centralized biopolitical state is a threat to individual liberties about which we should be concerned. He notes that the process by which particular freedoms are defined, managed, and subjected to suspension is a process that “leads not only to centralization and state violence but also to rights that channel the exercise of state power, to pervasive regulation of our lives and environment but also to a significant amount of predictability and security for many people.” *Id.* at 877.

⁹⁸ Kathryn Hinsch, Remarks at the Center for American Progress Special Presentation on “Bioethics and Politics: Past, Present, and Future,” (Apr. 21, 2006) (transcript on file with author and available at www.americanprogress.org). See also Joshua E. Perry, *Biblical BioPolitics: Judicial Process, Religious Rhetoric, Terri Schiavo and Beyond*, 16 HEALTH MATRIX 2:553-650 (2006) (discussing the activities of Focus on the Family, Family Research Council, American Center for Law & Justice, and Southern Baptist Convention’s Ethics & Religious Liberty Council), JON B. EISENBERG, USING TERRI: THE RELIGIOUS RIGHT’S CONSPIRACY TO TAKE AWAY OUR RIGHTS 94-109 (2005) (detailing the interconnected money trail, political links, and think-tank machinery that supported Terri Schiavo’s parents throughout their battle

Strategically, conservatives have seized on bioethics as a way to build the society based on their values and their worldview, which I would argue is anti-science, pro-religion, anti-reproductive freedom, by aggressively framing how bioethical issues are considered. But just as importantly, there are important tactical implications. They're using it as a way to gear up their troops, to galvanize their base, to polish their image as protector's of society's values, and perhaps most importantly to divide progressives.⁹⁹

The national reputation of the Right to Life Committee and its state-based confederation of local advocacy organizations is well known. Among the lower profile conservative groups that Hinsch identifies is Americans United for Life (AUL).

AUL is an organization founded in 1971 that has “made a transition from previously a well established, well funded, pro-life law firm that was solely dedicated to overturning *Roe v. Wade* to one that encompasses a broader range of bioethical issues from embryo research, cloning, genetic engineering, and nanotechnology.”¹⁰⁰ Indeed, in March 2006, AUL, which has an annual budget of \$1.4 million, released the 520-page *Defending Life 2006: A State-by-State Legal Guide to Abortion, Bioethics, and End of Life*.¹⁰¹ In short, this public policy manual is an exquisitely detailed battle plan for crafting incremental legislation that will result in a “pro-life America.”¹⁰² AUL promotes itself as “the nation’s foremost legal organization” working “hand in hand every day with state legislators, policy makers, and activists, helping pass laws” that “promote a culture

to block withdrawal of Mrs. Schiavo’s ANH), and R. Alta Charo, *Passing on the Right: Conservative Bioethics is Closer Than It Appears*, 32 JOURNAL OF LAW, MEDICINE & ETHICS 307 (2004) (discussing the President’s Council on Bioethics and its many political connections to religiously and politically conservative organizations).

⁹⁹ Kathryn Hinsch, Remarks at the Center for American Progress Special Presentation on “Bioethics and Politics: Past, Present, and Future,” (Apr. 21, 2006) (transcript on file with author and available at www.americanprogress.org).

¹⁰⁰ Kathryn Hinsch, Remarks at the Center for American Progress Special Presentation on “Bioethics and Politics: Past, Present, and Future,” (Apr. 21, 2006) (transcript on file with author and available at www.americanprogress.org).

¹⁰¹ DEFENDING LIFE 2006: A STATE-BY-STATE LEGAL GUIDE TO ABORTION, BIOETHICS, AND END OF LIFE [DEFENDING LIFE 2006] (Americans United for Life ed., 2006) (on file with author and available at www.AUL.org/defending_life).

¹⁰² DEFENDING LIFE 2006 at 5.

of life through the law.”¹⁰³ The editor of *Defending Life 2006* boasts that “state by state and law by law” AUL is “winning the battle to create a culture of life and to protect all human life from its earliest stages until its natural end.”¹⁰⁴

While the AUL’s “culture of life” agenda includes the advancement of legislation similar to the NRLC’s Model Act, opposition to experimentation on embryos, prenatal genetic screening, cloning, and assisted suicide, “its roots are in the abortion fight.”¹⁰⁵ Thus despite a recently expanded bioethical scope, AUL’s thirty year history has been focused on developing “a proven strategy to significantly reduce abortions . . . to create effective legal precedent that will lead to overturning *Roe v. Wade*, and to prepare for the . . . legal battles that will follow *Roe*’s reversal.”¹⁰⁶ The ultimate fight, therefore, is about eradicating abortion and regulating women’s bodies. To the extent that embryonic stem cell research or feeding tubes can be parlayed into a cause that will nudge the political climate in a direction that is more hospitable to a reversal of *Roe*, AUL is shrewdly prepared to fight its anti-abortion battle along these alternative, or proxy, culture war fronts.¹⁰⁷ Alta Charo analyzes the situation in these terms:

Finally, there is the awesome scale and scope of the abortion wars. In the absence of legislative options for outright prohibition, abortion opponents search for proxy wars, using debates on research involving human embryos, the donation of organs from anencephalic neonates, and the right of persons in a persistent vegetative state to die as opportunities to rehearse arguments on the value of biologic but nonsentient human existence.¹⁰⁸

¹⁰³ DEFENDING LIFE 2006 at 519.

¹⁰⁴ DEFENDING LIFE 2006 at 9.

¹⁰⁵ Jeanne Cummings, *Targeting Roe: In Abortion Fight, Little-Known Group Has Guiding Hand*, THE WALL STREET JOURNAL (Nov. 30, 2005) at A1.

¹⁰⁶ DEFENDING LIFE 2006 at 5.

¹⁰⁷ Ian Berry, *Schiavo’s Parents Relate Ordeal at Local Baptist Church*, CHATTANOOGA TIMES FREE PRESS (Oct. 4, 2005) at B1 (quoting Joshua E. Perry as seeing the drama surrounding Terri Schiavo as “another event in the ongoing culture wars.”).

¹⁰⁸ R. Alta Charo, *The Celestial Fire of Conscience—Refusing to Deliver Medical Care*, 352 NEW ENG. J. MED. 2471, 2472 (2005).

Supporters of the Model Act legislation might counter that of course there is a consistency between defending biologic nonsentient human life from conception all the way through to death. However, given the large numbers of feeding tubes withdrawn from incapacitated patients every year, one is left to wonder why the last fifteen months has seen the *Schiavo* case become the catalyst for the politicization of feeding tubes and end-of-life care at the bedside.¹⁰⁹ Those who would defend the Model Act and seek to dismiss the proxy war thesis must explain why long-term opponents of abortion have chosen Terri Schiavo and this particular historical moment to expand the scope of their biopolitical agenda to include the regulation of ANH.

Although the post-*Schiavo* movement to amend state laws and public policies regulating the provision of artificial nutrition and hydration to incompetent patients has not yet met with much legislative success, the biopolitical ethos of our day will undoubtedly continue to produce proxy wars in furtherance of a “culture of life” agenda. In the concluding remarks that follow, we will briefly consider the normative problems created by such an agenda of control in our age of biopolitics.

Conclusion

Commenting on the political interventions during Mrs. Schiavo’s final weeks of life, George Annas noted President George W. Bush’s repeated use of the phrase “culture of life” and its “not-terribly-subtle reference to the antiabortion movement in the United

¹⁰⁹ According to Steve Miles’s research, two million deaths occur every year in medical settings, and 85 to 95 percent of those are preceded by decisions to withhold or terminate life-prolonging interventions. Denise Grady, *Medical and Ethical Questions Raised on Deaths of Critically Ill Patients*, THE NEW YORK TIMES, July 20, 2006, at A18. See also E-mail from Steve Miles to Joshua E. Perry (July 20, 2006) (on file with author).

States.”¹¹⁰ Annas argued that “culture of life” politics is problematic at the bedside because it threatens to violate “a person’s body and human dignity in a way few would want for themselves.”¹¹¹ Instead of “erring on the side of life,” Annas argues that American values and constitutional traditions dictate that we err on the side of liberty and defend the patient’s right to decide on treatment.¹¹²

The push to change ANH laws in response to the Terri Schiavo tragedy appears to be, ultimately, about the biopolitical regulation of an incompetent patient’s death and the advancement of an anti-abortion agenda. Because the withdrawal of artificial nutrition and hydration is often an emotionally profound and often painful act undertaken by those entrusted to care for the patient, biopolitics has no place at the patient’s bedside. By this I mean that regulatory intervention that, in the absence of a sufficiently *authorized* and *applicable* living will, presumes to dictate the means and manner in which the bodies of incompetent individuals must be treated vis-à-vis the removal of life-prolonging technology is a biopolitics that is inconsistent with our best traditions of liberty and self-determination.

The U.S. Supreme Court has characterized this discussion in terms of the right to bodily integrity and freedom from unwanted touching.¹¹³ The very notion of individual rights, however, is only triggered by the assumption that a rational public interest in preserving life validates the regulation of an individual’s choice to receive ANH at the end of life. And so, we can clearly see that a tension exists between the private individual and that segment of the community advocating a “culture of nonsentient

¹¹⁰ George J. Annas, “*Culture of Life*” Politics at the Bedside—The Case of Terri Schiavo [“*Culture of Life*”], 352 NEW ENG. J. MED. 1710, 1710-15 (2005).

¹¹¹ Annas, *Culture of Life*, at 1714.

¹¹² Annas, *Culture of Life*, at 1714.

¹¹³ *Cruzan v. Director, Mo. Dept. of Health*, 497 U.S. 261, 278-79 (1990).

human existence.” We should expect this tension to emerge again in future proxy wars, as biopolitical actors (of all ideological stripes) stand ready to push new laws that assert “strategies for the governing of life”¹¹⁴ and the state’s biopower “to make live and to let die.”¹¹⁵ At the bedside, in our most emotionally vulnerable moments, the premeditated use of such power—in the form of regulations and legislation designed to advance a grander culture of control objective relating to abortion politics—is an abuse that we must both recognize and resist.

¹¹⁴ Rabinow & Rose, *Biopower Today*, at 195-217.

¹¹⁵ FOUCAULT, LECTURES, at 241.