The Atlantic Divide

Paternalism and patient autonomy in the United States and Mediterranean Europe

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Holly Brubach was staring at the emergency room ceiling of the Ospedale Gaetano Pini of Milan.[1] Her ambulance driver had assured her he was taking her to the "best orthopedic hospital in the north of Italy." It was the summer of 2014, and she had hoped to spend the day visiting museums and shoe shopping. Instead she dislocated her hip. And so she waited on an emergency room gurney, staring at the ceiling, in pain, waiting for hours. Communication from staff was minimal. Nurses entered and injected her with substances without saying a word. At one point, Holly asked a nurse what pill they were giving her; the nurse sighed with annoyance. "It's standard, Signora." In the United States, Holly's doctors actively informed and involved her every step of the way – yet this Italian hospital expected nothing more than acquiescence and obedience from its patients. In a New York Times op-ed reflecting upon her experiences, Holly concludes, "back home, I viewed doctors as my partners in the healing process, but not here — my life was in these peoples' hands, and they would decide what information I needed."

The practice of withholding information and limiting patient involvement is common in Italian healthcare. For example, various surveys from 1994 to 2009 indicate that less than 45% of Italian doctors fully disclose cancer diagnoses and prognoses to terminally-ill patients.[2] If they do disclose this information, they do so only via euphemisms or to a family member instead.[3] These practices are not limited to just Italy: studies observe similar practices in France, Portugal, Spain and Greece.[4] Mediterranean physicians do not act this way out of malevolence; rather, they genuinely believe that non-disclosure is in the patient's best interest and shields the patient from emotional harm.[5] Nevertheless, these paternalistic practices starkly contrast those in North America and the rest of Europe, where informed consent and patient autonomy are considered tenets of good physicianship.[6] Clearly, the notion of 'doing good' in medicine has diverged between North America and Southern Europe.

Surprisingly, this divergence is relatively recent. In fact, until the mid-20th century, the medical paternalism found in Italy and France was the prevalent practice that governed all of Western medicine. Yet in the 1960s, a series of scandals surrounding medical research practices in the United States

[1] Holly Brubach, "A Dislocated Tourist in Italy," *New York Times*, July 20, 2014, SR9.
[2] Arantza Meñaca et al., "End-of-Life Care across Southern Europe: A Critical Review of Cultural Similarities and Differences between Italy, Spain and Portugal," *Critical Reviews in Oncology/Hematology* 82 (2012): 390.
[3] Ibid.
[4] See Kyriaki Mystakidou, "Cancer Information Disclosure in Different Cultural Contexts," *Support Care Cancer* 12 (2004): 147–54; Kristina Orfali, "Parental role in medical decision-making: fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units," *Social Science & Medicine* 58 (2004): 2009-22; Patrick Peretti-Watel et al., "Disclosure of Prognosis to Terminally Ill Patients: Attitudes and Practices among French Physicians," *Journal of Palliative Medicine* 8, no. 2 (2005): 280-90.
[5] Alex J. Mitchell, "Reluctance to disclose difficult diagnoses: a narrative review comparing communication by psychiatrists and oncologists," *Support Care Cancer* 15 (2007): 819-28.
[6] Donna L. Dickenson, "Cross-Cultural Issues in European Bioethics," *Bioethics* 13, no. 3/4 (1999): 249-55.

precipitated a crisis of confidence in medicine, prompting far-reaching political reforms to rebalance the patient-doctor relationship. Owing to several historical factors, a similar crisis failed to occur in Mediterranean Europe. Nevertheless, the persistence of paternalism in Southern Europe remains in question, as it faces new and emerging sociopolitical threats.

I. Western medicine and the tradition of paternalism

Informed consent and shared decision-making are cornerstones of American medicine. However, this was not always the case. As recently as 1961, a survey of American oncologists found that 90% preferred to not share cancer diagnoses, because they feared that it would dampen the patient's spirits and worsen their condition.[7] Another 1973 journal article describes how American ICU neonatologists would often exclude parents from decision-making processes in order to absolve them from anguish or guilt.[8]

In fact, medical paternalism is a tradition that dates back to the beginnings of Western medicine. In *Decorum*, Hippocrates advises physicians to practice their craft "calmly and adroitly, concealing most things from the patient while attending him" and "revealing nothing of the patient's future or present condition."[9] The Hippocratic Oath, meanwhile, makes no reference to principles of communication, disclosure, or consent.[10] In Hippocratic medicine "skilled communication in care and deference to the patient's preferences are foreign ideas, except insofar as dialogue could be used to instill confidence and 'persuade' of a therapeutic regimen."[11] Although few healers in Ancient Greece followed Hippocratic dicta, the texts acquired immeasurable authority beginning in the Middle Ages, when they became centerpieces of Medieval-era medical curricula in the first medical schools.[12] As a result, Hippocratic teachings became a foundation of Western medical thought and key components of Western medical education during the Middle Ages, Renaissance, and Enlightenment.[13]

One can appreciate the influence of Hippocrates upon Western medical thought in several European writings addressing the subject of medical etiquette and morals. One example is *Medical Ethics*,

[7] Donald Oken, "What to Tell Cancer Patients: A Study of Medical Attitudes," *Journal of the American Medical Association* 175, no. 13 (1961): 1120-28.
[8] Anthony Shaw, "Dilemmas of Informed Consent in Children," *New England Journal of Medicine* 289 (1973): 885-90.
[9] W.H.S. Jones, *Hippocrates* (Cambridge: Harvard University Press, 1923), 2:297-99.
[10] Ibid., 1:289-302.
[11] Ruth R. Faden & Tom L. Beauchamp, *A History and Theory of Informed Consent* (Oxford: Oxford University Press, 1986), 62.
[12] Ibid., 63
[13] Jay Katz, *The Silent World of Doctor and Patient* (Baltimore: Johns Hopkins University Press, 1984), 7-25.

published in 1803 by English physician Thomas Percival.[14] In his book, Percival admits that patients have a right to know the truth about their medical condition – however, this right is "suspended, and even annihilated" in situations where the information "would be deeply injurious to the patient."[15] The physician should avoid "making gloomy prognostications" – if information is to be divulged, it should be told first to the family, and only to the patient "if absolutely necessary." [16] Percival's *Medical Ethics* is significant because it later formed the basis of the American Medical Association's first Code of Medical Ethics in 1847.[17] In fact, several of the code's passages were taken verbatim from Percival, including his advice to withhold information from patients with "gloomy prognostications."[18] Percival's view of medical ethics gained wide acceptance within American medicine, and it "gradually became the living creed of professional conduct in the United States."[19] Although the AMA later revised its code in 1903, 1912, 1947 and 1957, these revisions simply excised rather than replaced any paternalistic language.[20] From its inception until 1980, "[the Code's] viewpoint on the patient physician relationship remained largely unchanged."[21]

II. The institutionalization of bioethics in the United States

In 1961, 90% of American doctors preferred not disclosing cancer diagnoses to patients.[22] Yet only eighteen years later, 97% indicated a preference for revealing such a diagnosis.[23] What caused this dramatic shift in physician attitudes? Although one can certainly find some early examples of physicians who advocated for greater transparency between doctor and patient, the principles of patient autonomy and informed consent did not emerge from within physician circles. Their roots can be traced to social, legal and political debates surrounding research of human subjects during the 20th century.

[14] Thomas Percival, *Medical Ethics, or a Code of Institutes and Precepts, Adapted to the Professional Conduct of Physicians and Surgeons* (Manchester: S. Russel, 1803).
[15] Cited in Faden & Beauchamp, *Informed Consent*, 68-69.
[16] Cited in Katz, *Silent World*, 18.
[17] Katz, *Silent World*, 20-21.
[18] Faden & Beauchamp, *Informed Consent*, 69.
[19] Ibid., 70.
[20] Katz, *Silent World*, 22.
[21] Faden & Beauchamp, *Informed Consent*, 74.
[22] Oken, "Cancer Patients."
[23] Dennis H. Novack et al., "Changes in Physicians' Attitudes Toward Telling the Cancer Patient," *Journal of the American Medical Association* 241 (1979): 897–900.

Human experimentation is "as old as medicine itself," stretching as far back as the Ptolemaic era of Ancient Egypt.[24] Yet even though it was often unregulated, prior to the 1940s, human experimentation was also rare, limited in scope, and thus incited little controversy.[25] This changed with the outbreak of World War II. The war provoked a dramatic increase in the scale of medical research, as governments desperately pursued any means to bolster the war effort.[26] Many of these experiments were unethical, a case example being the atrocities committed by Nazi doctors upon concentration camp populations. Their actions became a topic of intense public discussion after the war ended. Yet although their trials for war crimes remain a landmark moment in the history of medical ethics, they had little actual impact upon research practices outside Germany. In the eyes of the American public, the doctors' actions were a consequence of Nazi ideology, rather than the absence of ethics regulations.[27] In fact, with breakthroughs such as penicillin and the polio vaccine, American faith in medical research reached unprecedented highs soon after the end of World War II, and it only continued to grow throughout the 1950s.[28]

Opinion began to change during the 1960s, however, with a series of exposés and court trials involving clinician-scientists. These scandals ranged from a Brooklyn physician interested in studying tumor immunology who injected live cancer cells into his patients without their consent, to a Staten Island physician who deliberately infected hundreds of mentally challenged children with hepatitis as part of his studies to develop a prophylactic agent.[29] The controversy grew in 1966, when Henry Beecher described 22 instances of questionable human subject research in an article published in the New England Journal of Medicine.[30] Yet the impetus for reform only arrived even later, in 1972, when the New York Times broke the story of the Tuskegee syphilis study.[31] For over 40 years, the newspaper revealed, government researchers had been studying the pathological effects of syphilis in a cohort of 200 African-American men, even after standardized antibiotic treatment became available in 1947. The revelations were especially shocking given their timing, six years after the Civil Rights Act.[32] In response to Tuskegee, the

[24] Paul Murray McNeill, *The Ethics and Politics of Human Experimentation* (Cambridge: Cambridge University Press, 1993), 17.
[25] David J. Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (New York: Basic Books, 1991), 34.
[26] Rothman, *Strangers,* 36.
[27] Jay Katz, "The Consent Principle of the Nuremberg Code," in *The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation*, ed. George Annas and Micheal A. Grodin (New York: Oxford University Press, 1992), 228.
[28] Paul Starr, *The Social Transformation of American Medicine* (New York: Basic Books, 1982), 335.
[29] Faden & Beauchamp, *Informed Consent*, 161-64.
[30] Ibid., 159.
[31] Ibid., 165-67.
[32] Rothman, *Strangers*, 14.

United States Congress established a committee to review federal research guidelines, which later published its recommendations as the Belmont Report in 1979, and Congress later codified into law.[33]

Yet these scandals went beyond impacting federal research guidelines. They also eroded the American public's trust in doctors, given that many of the accused researchers were also physicians: "a reluctance to trust researchers to protect the well-being of their subjects soon turned into an unwillingness to trust physicians to protect the well-being of their patients."[34] As the number of scandals expanded, the perception grew that doctors could no longer be trusted to govern themselves. The controversy exposed medicine to outside scrutiny: "the authority that an individual physician had once exercised covertly was now subject to debate and review by colleagues and laypeople."[35] Philosophers began examining the patient-doctor relationship in a series of conferences during the 1960s, and later founded permanent academic forums devoted to the study of medical ethics, such as the Hastings Center in 1969 and the Kennedy Institute in 1970.[36] Meanwhile, the crisis compelled courts to develop a legal basis for patients' rights, beginning with *Salgo v. Leland Stanford Jr* in 1957, the first court decision to employ the term "informed consent."[37]

The timing of these events during the 1960s is especially important. This decade marked the emergence of new social movements centered upon the promotion of self-determination and human rights.[38] These movements – civil rights, women's rights, and gay rights – espoused "a profound suspicion and distrust of constituted authority," as well as "fierce anti-paternalism, a dogged rejection of the principles of beneficence, [and] a persistent determination to let constituents speak for themselves."[39] It is within this ideological undercurrent that modern bioethical thought arose.[40] It is also within this context that courts began establishing a legal basis for patients' rights. The key turning point occurred in 1972, with *Canterbury vs. Spence*. The landmark court decision significantly expanded the concept of informed consent first introduced in *Salgo*, by asserting that patients can only truly exercise self-determination if they are fully informed of *all* the risks and alternatives associated with a medical decision or procedure.[41]

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[33] Faden & Beauchamp, *Informed Consent*, 215-218
[34] Rothman, *Strangers*, 22.
[35] Ibid., 6.
[36] Alfred I. Tauber, "Historical and Philosophical Reflections on Patient Autonomy," *Health Care Analysis* 9 (2001): 301.
[37] Katz, *Silent World*, 60.
[38] Nelson A. Pichardo, "New Social Movements: A Critical Review," *Annual Review of Sociology* 23 (1997): 414.
[39] David J. Rothman, "The Origins and Consequences of Patient Autonomy: A 25-Year Retrospective," *Health Care Analysis* 9 (2001): 256.
[40] Tauber, "Reflections," 302.
[41] Faden & Beauchamp, *Informed Consent*, 133.

The decision thus dramatically increased the amount of information that doctors were required to disclose to patients, effectively legally mandating doctors to share decision-making with patients.

As courts established the legal doctrine of patients' rights, the number of medical malpractice lawsuits began to skyrocket. Malpractice claims rose seventeen-fold between 1960 and 1980,[42] and insurance premiums increased by 500%.[43] Two unique idiosyncrasies of the American legal system allowed the emergence of the 1970s "malpractice crisis." First, lawyers in the United States can advertise their services, facilitating the process of finding potential claimants.[44] Second, American lawyers can assume all financial risks associated with a lawsuit, which eliminates the financial disincentives of taking legal action.[45] The 1970s malpractice crisis ultimately acted as a powerful enforcement mechanism of patients' rights, and in the decades that followed, it drastically recalibrated the doctor-patient relationship.

III. The persistence of paternalism in Mediterranean Europe

While the patient-doctor relationship in the United States experienced radical transformation during the 1970s, it remained largely unchanged in Southern Europe. In Europe, the crucial element that initiated the bioethics movement in the United States was missing: the dramatic expansion of human subject research. While the United States experienced a research boom during the postwar years, the Second World War left European research infrastructure literally in ruins. The war destroyed laboratories, disrupted scientific training, and provoked an exodus of European researchers towards the United States.[46] Immediate concerns such as agriculture, housing and energy dominated the postwar agenda.[47] Interest in rejuvenating European research only emerged during the 1950s – however, medical research was not a priority. Instead, the dawn of the postwar atomic age lured European governments into making particle physics and nuclear science the centerpiece of their research initiatives, starting by founding the European Organization for Nuclear Research (CERN) in 1954.[48] The appetite to rejuvenate European

[42] Donald N. Dewees et al., "The Medical Malpractice Crisis: A Comparative Empirical Perspective," *Law and Contemporary Problems* 54, no. 1 (1991): 219.
[43] Patricia Munch Danzon, *Medical Malpractice: Theory, Evidence, and Public Policy* (Cambridge: Harvard University Press, 1985), 2.
[44] Jacques-Michel Grossen and Olivier Guillod, "Medical Malpractice Law: American Influence in Europe?" *Boston College International & Comparative Law Review* 6, no. 1 (1983): 24.
[45] Ibid., 25
[46] John Krige, *American Hegemony and the Postwar Reconstruction of Science in Europe* (Cambridge: MIT Press, 2006): 32.
[47] Luca Guzetti, *A Brief History of European Research Policy* (Luxembourg: Office for Official Publications of the European Communities, 1995): 2.
[48] Ibid, 1-2.

medical research only truly appeared during the late 1960s – and by then, the United States research complex was already beginning to experience radical changes in regulation and practice.[49]

Many scholars in Europe closely followed the rise of patients' rights in the United States. However, few initially saw any value in bioethics. Doctors still enjoyed considerable esteem and trust in European society. In fact, many European scholars at first ridiculed American bioethics "as a new fashion created by Yankee imperialism."[50] Interest in bioethics only truly emerged in Europe beginning in the 1980s, with the development of new medical technologies such as in-vitro fertilization. The technologies raised new ethical and moral questions, provoking heated debate within the European public.[51] Bioethics offered a means of exploring these questions. It is during this period that the first European institutions dedicated to the study of bioethics were founded, such as the French National Ethics Commission in 1983 and the Italian Center for Bioethics at the Catholic University of Rome in 1985.[52] However, reflecting the circumstances that prompted its emergence, the European study of bioethics "was conceived not as one component of a larger movement of critical reflection on health care, but as a set of related issues (mainly focusing on birth and death) with no clear systematic links to each other."[53] In sharp contrast with the American bioethics, which was a broad political movement that articulated prevailing social preoccupations with the practice of medicine, European bioethics was a project of fairly limited scope and ambition, nothing more than a lens to study a set of provocative moral issues.

During the 1990s, after a push by the World Health Organization, several European governments passed new legislation in order to formally recognize patients' rights.[54] In 1998, Italy reformed its medical deontological code to legally recognize informed consent and patient autonomy for the first time.[55] In a 2002 patients' rights law, France for the first time legally mandated doctors to provide patients "all the necessary preliminary information" associated with a medical procedure or decision.[56] Yet despite these reforms, doctors in Southern Europe still possess substantial discretion in medical decision-making. For example, "the new deontological code in Italy is silent [on many vital questions], e.g. in relation to advance

[49] Ibid., 58.
[50] Maurizio Mori, "The Discourses of Bioethics in Western Europe," in *The Cambridge World History of Medical Ethics*, ed. Robert B. Baker and Laurence B. McCullough (Cambridge: Cambridge University Press, 2012), 491.
[51] Ibid.
[52] Ibid.
[53] Ibid.
[54] Lars H. Fallberg, "Patients' Rights in Europe: Where Do We Stand and Where Do We Go*?" European Journal of Health Law* 7 (2000): 1.
[55] Antonella Surbone et al., "Evolution of Truth-Telling Attitudes and Practices in Italy," *Critical Reviews in Oncology/Hematology* 52 (2004): 167.
[56] Nora Moumjid and Marie-France Callu. "Informed consent and risk communication in France," *British Medical Journal* 327, no. 7417 (2003): 734–735.

directives. Here the professional's duty of beneficence is presumed to fill in the gaps."[57] A similar problem exists in France, where physicians work "in a legal vacuum" where "the law does not specify explicitly what is or [is] not permissible."[58] French physicians thus end up developing their own personal professional and ethical criteria.[59] Even if these new laws in Southern Europe are further strengthened, patients' rights in Southern Europe faces several challenges. Many Italian and French doctors (and patients) perceive bioethics "as something foreign, or at least as something different from the Mediterranean ethical tradition" and are skeptical of laws founded upon foreign "Anglo-American" values.[60]

Patients possess little power to change the patient-doctor power structure. Patients' rights groups are nascent and possess little power.[61] European courts lack many of the idiosyncrasies of American courts that allowed the explosion of malpractice in the U.S, limiting the enforcement of new patients' rights legislation.[62] In sum, Southern Europe lacks many of the sociopolitical factors that engendered the push to reform the patient-doctor relationship in the United States.

Conclusion

Despite the persistence of paternalism in Southern Europe, several trends suggest that as in the United States several decades before, sociopolitical and legal forces may be coalescing once again to alter the balance of power between doctor and patient in France and Italy. Harmonization of legislation within the European Union could give rise to stronger patients' rights legislation.[63] Ongoing public controversies regarding abortion, euthanasia and in-vitro fertilization foment continued interest in the relationship between medicine and society, further fueled by the proliferation of health talk shows and medical dramas in the media.[64] European patient advocacy groups are building political and social capital.[65] In addition, a new force threatens to erode the physician's authority and empower patients to take more control of their medical care: the Internet. Traditionally, health providers were the main providers of

[57] Dickenson, "Cross-Cultural Issues," 252.
[58] Orfali, "Parental Role," 2012.
[59] Ibid.
[60] Diego Gracia, "The Intellectual Basis of Bioethics in Southern European Countries," *Bioethics* 7, no. 2 (1993): 98.
[61] Rob Baggott & Rudolf Forster, "Health Consumer and Patients' Organizations in Europe: Towards a Comparative Analysis," *Health Expectations* 11, no. 1 (2008): 85-94.
[62] Grossen & Guillod, "Medical Malpractice Law," 24-25.
[63] Jacob Dahl Rendtorff, "Basic Ethical Principles in European Bioethics and Biolaw: Autonomy, Dignity, Integrity and Vulnerability – Towards a Foundation of Bioethics and Biolaw," *Medicine, Health Care and Philosophy* 5 (2002): 240.
[64] Surbone, "Evolution of Truth-Telling," 167.
[65] Fallberg, "Patients' Rights," 3.

health information, allowing them to fully control what patients knew and didn't know. However, given the abundant amount of easily accessible information on the internet, patients can now shift from being "passive recipients to more active consumers of health information."[66] Evidence suggests patients in Southern Europe are increasingly using the Internet to learn about their conditions, which threatens to erode the physician's ability to selectively disclose only certain information to their patients.[67] The physician's authority faces encroachment from multiple fronts in Southern Europe, and if the patient-doctor relationship experiences radical transformation in the future, it wouldn't be the first time that history had repeated itself.

In response to these trends, some Mediterranean scholars have argued for a "remaking" instead of an "importing" of American bioethics. For example, Spanish bioethicist Diego Gracia has suggested the creation of a new "Latin" model of bioethics based upon "a tradition shaped by classical Greek philosophy and ethics" which emphasizes trust and friendship between doctor and patient, as opposed to the business-like and transactional demeanor of the Anglo-American model.[68] This type of patient-doctor relationship would place the doctor in the best position to decide what is best for the patient, even if this means not disclosing a diagnosis. And to some extent, this view has an empirical basis: in the United States, many studies find that some patients do *not* want to be involved in their care, and in fact prefer to defer decision-making to their physicians. For example, in a systematic review of 115 patient surveys, 21% of the analyses found that the majority of respondents preferred to delegate decisions to a physician.[69] To make matters more complicated, a patient's decision-making preferences can change over time, depending on the patient's age, the disease course, or the health professional they are dealing with.[70] In the end, the future of the patient-doctor relationship may not be about the triumph of one orthodoxy over another, but rather about what each side can learn from one another.

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[66] Miriam McMullan, "Patients Using the Internet to Obtain Health Information: How This Affects the Patient–Health Professional Relationship," *Patient Education and Counseling* 63 (2006): 27.
[67] Surbone, "Evolution of Truth-Telling," 166.
[68] Gracia, "Intellectual Basis," 98-101.
[69] Betty Chewninga et al., "Patient Preferences for Shared Decisions: A Systematic Review," *Patient Education and Counseling* 86, no. 1 (2012): 9-18.
[70] Rebecca Say, et al., "Patients' Preference for Involvement in Medical Decision Making: a Narrative Review," *Patient Education and Counseling* 60 (2006): 102-14.

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