Published in final edited form as:

Med Anthropol Q. 2011 June ; 25(2): 209–231.

Medicare, Ethics, and Reflexive Longevity: Governing Time and Treatment in an Aging Society

Sharon R. Kaufman and

Department of Anthropology, History and Social Medicine, Institute for Health and Aging,
University of California, San Francisco

Lakshmi Fjord

Institute for Health and Aging, University of California, San Francisco

Abstract

The clinical activities that constitute longevity making in the United States are perhaps the quintessential example of a dynamic modern temporality, characterized by the quest for risk reduction, the powerful progress narratives of science and medicine, and the personal responsibility of calculating the worth of more time in relation to medical options and age. This article explores how medicine materializes and problematizes time through a discussion of ethicality—in this case, the form of governance in which scientific evidence, Medicare policy and clinical knowledge and practice organize first, what becomes “thinkable” as the best medicine, and second, how that kind of understanding shapes a telos of living. Using liver disease and liver transplantation in the United States as my example, I explore the influence of Medicare coverage decisions on treatments, clinical standards, and ethical necessity. Reflexive longevity—a relentless future-thinking about life itself—is one feature of this ethicality.

Keywords

bureaucratic rationality; technological innovation; bioethics; liver transplantation; U.S. society

Anticipatory Medicine

The emergence of “the timing of death” as a focus for individual–clinical control has become ubiquitous in U.S. society, and that preoccupation, together with the desire to “grow older without aging” (Miller 2006) are two dimensions of a dynamic modern temporality in an aging society. In “advanced liberal” sectors of society (Rose 1996) that temporality is expressed through the quest for health promotion and risk reduction and by “living in prognosis” (Jain 2007), that is, a way of knowing and living that is oriented toward probabilities of the timing of death in the context of disease. Overall, contemporary temporality is infused with a sensibility of *anticipation* (Adams et al. 2009) in which the future is made present via risk assessment strategies (Beck 1992), is privatized via the neoliberal emphasis on individual choice and responsibility (Crawford 2006; Guyer 2007), and is embodied in need and obligation.

The activities that constitute longevity making in the United States are perhaps the quintessential example of this temporality at work, and they highlight the pervasive role that biomedicine—as institution, system of knowledge, and set of practices—plays in everyday life. Medicine in the United States, unlike in Europe, exists in a cultural milieu that stresses

longevity by any means and at any cost. The powerful progress narratives of science and medicine are alive and at work in all longevity-making realms: bioscientific discovery; Medicare policy; evidence-based medicine; the technological imperative, standards of care, and the ethics that follow; and consumer demand. Importantly, medicine, through the clinical encounter, links ideas of biomedical progress to each individual's life course (Wilk 2007:441). Treatments and the hope associated with them further personalize the "colonization of the future" (Giddens 1991) and the anticipatory nature of contemporary life.

For older persons in the United States who are enabled by Medicare to access much that the clinic offers,¹ that linkage forces a calculation about how much more time is wanted in relation to age. The future has a short horizon (relative to younger adults) already. That future is brought into the present in the joined scenarios that medicine sets up for seriously ill older persons—the risk of death and the potentiality of avoiding death a bit longer; and the condition of being already (relatively) near the end of the "natural" lifespan against the hope of extending life through biotechnological intervention. Medicine thus materializes time (Wilk 2007) in its therapies that offer the possibility of a certain number of additional weeks, months, or years.

Temporality and Ethicality

This article explores how medicine materializes and problematizes time, and how it brings the future into the present. I illustrate these phenomena with the example of liver disease, liver transplantation, and the role Medicare plays in facilitating treatment. I choose this example because it shows the growing disease burden in the U.S. aging population and because it is emblematic of the rising age for procedures of all kinds, but especially high tech procedures. Through ethnography and a discussion of disease burden and Medicare coverage trends, I show how the links among progress, each patient's life, and the potential for an open-ended future are forged.

This example includes three characteristics, all of which are typical of the biomedical and infrastructural arena of U.S. health care delivery today: Medicare payment coverage trends; evidence-based medical knowledge that shapes Medicare policy and thus clinical practice; and the production of patient and family need for more treatment into ever-later life. Those characteristics, taken together, constitute and "produce" longevity making in the United States today. They are the essential features of a form of governance I term *ethicality*, because *the ethical*—I will show—is embedded in public policy through two mechanisms: first, the supreme value placed on medical rationality and its instrumentalization in technological innovation and technology use; and second, the structures of research, industry, and evidence making, which, together, emphasize the efficacy of new technologies (or new indications for older technologies) and then legitimate and pave the way for insurance reimbursement of them.

The organization of Medicare reimbursement to doctors and hospitals rewards the use of technologies and those who invent and deploy them. It does not support low-cost, alternative forms of caring (Callahan 2009a:11). The societal press to seek and employ drugs, devices, and procedures, regardless of end-stage medical conditions and patient age, and irrespective of financial burden to families or social costs to the nation, is a particularly U.S. phenomenon, in which progress and individual aspiration are manifest in technological know-how and technical solutions. The high moral value placed on technological intervention (with emphasis on the new and the costly) and technical efficacy is supported by the structures of private industry, science, and evidence making and the priority given to

¹Medicare is the U.S. government program that pays for acute medical care for persons age 65 and over.

rational–technical ways of knowing in clinical practice (Good 1994). That moral value is embedded in and enacted through Medicare reimbursement policies and the private insurance policies that follow.

That conjoining of moral value with technological priority through the rationalities of scientific evidence and government policy about insurance coverage is a form of ethics in and of itself.² In addition, that conjoining influences individual health outcomes and the timing of death and so shapes physician, patient, and family understandings of, qualms about, and actions regarding the right thing to do in the face of life-threatening disease. Questions about doing “the right thing” vis-à-vis potential, hovering death becomes a major existential and cultural preoccupation and constitutes a primary ethical feature of U.S. health care delivery. This is the dual sense in which I speak of *ethicality* as a form of governance.³

This form of governance, *ethicality*, is largely invisible. By that I mean that the different stakeholders involved in the chain of connections between scientific discovery and clinical use—biomedical scientists, clinical researchers, Medicare policymakers, clinic administrators, physicians, patients, and families—are not specifically aware of the way in which the strong value of the technological operates at every stage between invention and reimbursement, between scientific evidence and individual choice, to shape a system of bureaucratic rationality in which treatment coverage decisions, and therefore standards of care and the contours of ethical necessity, are determined. My goal is to expose some of the connections among Medicare coverage trends, clinical knowledge, treatment rationales, and their effects on patient and family choice, anxiety, and self-awareness to make the workings of this naturalized *ethicality* visible.⁴

The term *ethicality* captures and reinforces what Dean has called the “enfolding of authority” (Dean 1996:221–226)—in this case, the embedding of the moral authority contained in Medicare policy and clinical practice with the knowledge, self-discipline, and responsibility that stresses life-prolonging activity at ever-older ages. Through this “enfolding of authority,” we—health providers and health care consumers—become calculable to ourselves, governable, in particular ways. That is, doctors, patients, and their families (in the United States) live within and thus respond to the primacy of the moral authority that links technological innovation and technical efficacy with reimbursement and thus with personal responsibility for choosing or rejecting technological solutions to life-threatening disease. I focus on *ethicality* in the clinical realm, when life is at stake, as “the relation between the forms of truth by which we have come to know ourselves and the forms

²Thanks to Sarah Horton for emphasizing this point.

³My use of the term *governance* is indebted ultimately (although not directly) to Foucault’s idea of governmentality, in which he describes modern political regimes as ruled by “techniques of government,” rather than “structures of sovereignty” (1991:101) and in which the population is “aware, vis à vis the government, of what it wants” (1991:100). Foucault describes governmentality in part by “the calculations and tactics that allow the exercise of this very specific albeit complex form of power, which has as its target population, as its principal form of knowledge political economy, and as its essential technical means apparatuses of security” (1991:102). This multiplex idea of power is relevant to my observations and argument. However, in this article I am more influenced by the ways in which the terms *government* and *governance* have been taken up by others in considering Foucault’s idea of governmentality vis à vis contemporary situations. Thus, I am interested in: the relationship between the conduct of political reason and the conduct of individual lives; the practices and exercise of freedom; the relations among authority, identity, and responsibility for our own lives; and the ways in which technologies normalize populations. See particularly Becker 2007; Burchell 1996; Dean 1996; and Rose 1996, 2007. I am informed, as well, by Fassin, who explores “the issues at stake in the practices of government” (2009:48) and the idea, elaborated by other scholars also, that “the ‘right to health’ is more than social and economic, it is civil and political” (Fassin 2009:51).

⁴I follow anthropological convention in my use of the term *naturalized* here. Anthropologists use the term in reference to cultural practices, structural apparatuses, or ways of knowing that have become normal, unremarkable, and thus not acknowledged for their role in organizing social life. For example within the U.S. health care arena—surrogacy, fetal surgery, living donor organ transplant, cardiac bypass performed on nonogenarians, tube feeding of the demented elderly, and so forth, are all practices that are taken for granted, unquestioned regarding their sources and ordinariness and thus assumed to be natural to a particular social milieu.

of practice by which we seek to shape the conduct of ourselves and others” (Dean 1996:220).

In the clinical realm *ethicity* refers to the process through which political decisions, bureaucratic structures and clinical knowledge and practice, together, organize first, what becomes “thinkable” as the best medicine for very sick persons, and second, how that kind of understanding works on the self, to give shape to a telos of living (Lakoff and Collier 2004:431). In the example of liver disease and treatment, I look at the influence of Medicare coverage decisions on treatments and clinical standards, and at how those two phenomena shape questions of how to live.

Ethicity Is Not Bioethics

I use the term *ethicity* to emphasize ethical rationality as constituted in and through political-economic structures, the organization of treatment practices and their effects on health providers and consumers, and as located throughout the social fabric and enabled through the routines of clinical care. This way of conceptualizing the ethical as part and parcel of a broad sociostructural terrain moves away from earlier conceptions and uses of *bioethics* (beginning in the late 1960s), which assumed that problems in medicine were located at the level of the doctor-patient relationship and, therefore, stressed improved communication, analysis of conflicting values, and rational, autonomous decision making between the physician and patient at the bedside, mostly in situations in which choices about life-prolonging, death-defying procedures were being made.⁵

The ethics I describe here stands on the shoulders of, and displaces, that older kind of ethics,⁶ which emerged as well in the social justice debates in the 1960s, about rationing dialysis to “deserving” citizens, and in the concern, beginning in the 1970s with Karen Quinlan,⁷ about who has the authority to withdraw life-sustaining treatment from whom, and when. Although the normative concerns central to the bioethics enterprise remain (what ought to be done), and while the issues of allocation, selection, and responsibility for “life” and “death” at the bedside certainly linger, more complex patterns of health care delivery organization and fragmentation have emerged in recent decades. Those have been constituted in part by an explosion in (global) clinical research that affects health care finance and treatment distribution, and by a greater array of diagnostic and life-sustaining technologies that can and do make end-stage diseases into chronic conditions in which doctor management and patient discipline are key. Thus, different kinds of structures contribute to and constitute the *ethical* today.⁸ More than ever before, the politics and economics of health care delivery, together with powerful technologies and the bureaucracies that facilitate their use, impinge deeply on the practice of medicine and on the lives of patients and families.

In sum, the ethics I describe here is “located” in and shaped by health care policies, standard and emerging technologies, and the clinical evidence that supports technology use

⁵See Bosk 1999 and Fox 1991 for discussion of the subject matter and limitations of the bioethics enterprise.

⁶Renee Fox (and others) noted nearly two decades ago that bioethics has focused on a specific set of moral quandaries and disregarded the social, cultural, and structural contexts in which choice making is embedded (1991). Fox specifically drew attention to the fact that “little consideration [is] given to the ethics of health-care organizations, or to the ethical ramifications of the dominant role that for-profit health organizations have come to play in the delivery of health care in the United States since the 1980s” (1999:12).

⁷This is also evident in the case of Terri Schiavo in 2005.

⁸In the past decade, social scientists and bioethicists have expanded their ideas regarding what constitutes ethical problems and the bioethics enterprise. For work on bioethics in the context of the lived experience of patients, providers, and the changing framings of moral issues, see Hoffmaster 2001. For a recent analysis of the changing field of bioethics and its relation to social science, see De Vries and colleagues 2007. The latter volume takes up the topics of research ethics, ethical relations among scientists, citizens, clinicians, and regulatory agencies, and the production of ethical norms and regulations themselves. For a probing account of the ethics of the global clinical trials industry, see Petryna 2009.

(illustrated in Part 1, below). It is constituted by what patients and families come to need and, therefore, to want (illustrated in Part 2). Ultimately, it emerges in the physical caregiving tasks and emotional burdens placed on families. Its logic and routines permeate every aspect of health care delivery and affect everyone—clinicians, patients, families, and health care consumers alike. The term *ethicality* points to and encompasses the linkages forged among clinical evidence, treatment priorities, health care financing, standards of care, the making of “routine” and “necessary” interventions, and the fact that those linkages determine provider and patient responsibility about lives at stake.

Making Longevity in the United States

The average age of persons who receive surgery or other nonprimary care interventions that extend life at older ages is rising rapidly. For example, cardiac bypass surgery, implantable cardiac devices, renal dialysis, and aggressive cancer treatments are all unremarkable at very advanced ages. These interventions are reshaping both medical knowledge and societal expectations about “normal” old age, longevity, and the time for death. Many formerly “end-stage” diseases can be managed for years, and practitioners and patients alike have learned to consider the body malleable, treatable at any age (President’s Council on Bioethics 2003).

Evidence-based clinical studies, accorded high value today for determining treatment standards, encourage and allow the Medicare program to expand its criteria for cost coverage of procedures. Private insurance schemes largely follow the lead of Medicare (Tunis 2004). In that way more disease treatments and more technologies for risk reduction become Medicare approved. Medicare approval instantly becomes, and thus comes to mean, standard of care (Bach 2009; Hlatky 2004; Neumann et al. 2005).

The determinative link between Medicare approval and standard of care is the crux of the matter here because “standard of care” means appropriate practice, difficult, if not impossible, for practitioners to ignore and for patients and families to turn down. Koenig pointed out two decades ago how the “technological imperative” in medicine becomes a moral imperative, and she showed that the shift in meaning occurs because new technologies almost immediately “feel” routine to practitioners and quickly become routinized. “Once a new technology is developed, the forces favoring its adoption and continued use as a standard therapy are formidable,” Koenig notes (1988:467). “Standard of care becomes a moral, as well as technical, obligation” (Koenig 1988:486). The effects of that phenomenon today are more far reaching than ever before because, in the culture of medicine, the technological imperative is bolstered by evidence-based studies that ensure “the good” of new therapies, sometimes regardless of their actual clinical outcomes (Gillick 2007). Technical ability and success become ethical necessity.

The organization of U.S. health care delivery—in which the rationale and hope of therapy come up against the cry to reduce suffering; in which options for more intervention meet “futility” known only after the fact; in which ever-emerging evidence of effective treatment does not mean effective for everyone and often clashes with cost, scarcity, and the social good; and in which technical ability becomes ethical necessity—can be termed *after progress*. “Progress” refers to the long-held Enlightenment idea that rationality and its tools can unequivocally improve life and reduce suffering. *After progress* critically reflects on the priority and effects of ever more technology use in an aging society, and it emphasizes that technical ability and ever more interventions, while extending wanted life for many, also bring with them fundamental social and existential quandaries. *After progress* is an uneasy, pervasive contemporary condition.

Part 1. Medicare—the Fulcrum of Ethicality

I begin with the ways in which one feature of government, Medicare policy, comes to work through “regimes of conduct” (Dean 1996)—that is, the rationales and actions taken regarding medical treatment. Using liver disease and liver transplantation as my example, I explore how Medicare policy organizes the ethical in health care delivery today. I ask, What becomes an ethical necessity—for doctors, patients, and families alike—and how? I aim to show that Medicare policy, through expansive eligibility criteria for certain interventions, not only creates access to them but also ensures their use. Medicare coverage decisions have enabled transplant medicine to flourish in the United States, and there is no doubt that those decisions contribute to prolonged lives.

I follow the work of Becker (2007) and Shore and Wright (1997) in their conceptualizations of policy as a “political technology” shaping subjectivity.⁹ I suggest that Medicare policy is a tool, a means of rationality and power that “works upon the individual’s sense of self” (Shore and Wright 1997:29) through the norms of truth and conduct it creates and promotes. Medicare policy has a legitimating function in that it rationalizes and organizes courses of action (Shore and Wright 1997:11).

Medicare coverage decisions authorize payment for particular life-extending treatments. Those coverage decisions allow for the distribution of resources, some of them extremely scarce, to specific groups. More broadly, those decisions embody values and priorities about, first, the kinds of structures of health care delivery the state should support, (e.g., transplant centers and the myriad research and clinical enterprises that flow to and from them), and, second, which therapies are worth covering for a group of patients, and for which conditions.

Committees working through the Centers for Medicare and Medicaid Services (CMS), which administers the Medicare program, continually recalibrate the kinds of treatments Medicare will pay for and the types of diseases and conditions it will consider under its coverage umbrella (Gillick 2007; Tunis 2004). Evidence-based assessments by the CMS of the overall risks and benefits of a drug, device, procedure, or service are the most important factor in determining reimbursement (Mendelson and Carino 2005). An independent committee of experts and stakeholders, the Medicare Coverage Advisory Committee, established in 1999, meets in public to consider coverage criteria for treatments as well (Tunis 2004). Other factors—physician lobbying groups, the device and pharmaceutical industries, private insurance, U.S. Congress—also contribute to reimbursement decisions. Because treatments for life-threatening cancers, cardiac diseases, and other conditions are common among the elderly, Medicare policies become fundamental to ways in which life can be lived for a growing segment of the population. Thus, Medicare is implicated, at its core, in the ethics of managing life. Through the governing work (Dean 1996) of Medicare policy, the U.S. government, and U.S. taxpayers, together, shape the conduct of longevity making for themselves and their loved ones.

The ethical decision making that takes place downstream is thus already prefigured by Medicare coverage policy. This includes decisions by universities and hospitals to hire the best surgeons and their support teams, to train surgeons and other specialists, and to purchase expensive equipment so they can participate in state-of-the-art diagnosis and treatment that responds to the newest evidence from clinical trials and other studies, thereby attracting patients and referrals by doctors. Further downstream it includes the practices of

⁹Here, *subjectivity* refers to the making of self-knowledge and identity within the arena of social–political–ethical participation. Subjectivity is mediated by institutional norms and cultural expectations.

individual physicians and patients regarding what to offer, whom to refer, and what to undergo. Those coverage policies encourage and support the flourishing of high tech treatments and thus frame responses—among medical center leaders, health professionals, patients, and families—to the fundamental question, how to live?

As Medicare adopts new technologies as the standard of care, it shapes and reshapes conceptions of which conditions are fatal, which are chronic and can be successfully treated. Medicare coverage policies for liver transplantation have broadened over time (similar to other treatments) so that, for persons age 65 and beyond, liver diseases previously fatal are now objects of treatment. All Medicare coverage decisions, not just in this case, exemplify at once rationing and access. Medicare does not pay for treatments in which the evidence base is weak by scientific standards. Medicare does, eventually, provide coverage for an intervention when enough evidence accumulates to show treatment efficacy (at least in clinical studies). In this way, Medicare coverage decisions authorize best practices through the acknowledgment that the evidence produced in clinical trials or in outcome studies is scientifically adequate to show (overall) safety and efficacy. Although they are based on technical criteria of safety and efficacy, coverage decisions are, in fact, ethical priorities because access, health, and survival are at stake.

Liver Transplantation, Medicare Coverage, and the Ethics of Managing Life

Liver transplantation provides a useful example of how developments in research and clinical practice pave the way for broader coverage of conditions. This example begins to open the “black box” of how Medicare policy making produces the ethical today. The first human liver transplants were carried out in the 1960s. By the 1980s, with improvements in immunosuppressive drugs, liver transplantation had gained widespread acceptance and became the only curative treatment for certain liver diseases. Today they are the second-most common organ transplant operation (after kidney) in the United States,¹⁰ and they are performed in 127 U.S. centers¹¹; 6,320 individuals received liver transplants in 2009. Eleven percent of those went to persons age 65 and over (up from 10 percent in 2008).¹² Although those numbers are not large, the percentage of liver transplants for older persons is rising.

Payments to hospitals for liver transplants among Medicare beneficiaries began in 1991,¹³ but only for a limited number of diagnoses. Broader coverage for transplant as treatment of end-stage liver disease became available in 1996. Hepatitis B and liver cancer continued to be excluded from coverage because of the unsolved medical problem of disease recurrence following transplantation. By 1999, developments in molecular diagnostic and antiviral therapies had dramatically improved the prevention of recurrent hepatitis B viral infection after liver transplant. Medical literature suggested then that liver transplantation improved outcomes in patients with hepatitis B, and so that disease was no longer excluded from Medicare coverage.¹⁴

Liver cancer continued to be excluded from Medicare coverage in 1999 because the “evidence base” was not strong enough to indicate that outcomes for patients with liver cancer would improve with transplantation, according to analysis by the Centers for Medicare and Medicaid Services.¹⁵ By 2001, medical literature showed that outcomes for

¹⁰See <http://www.kidney.org/atoz>, accessed June 16, 2005.

¹¹See <http://www.unos.org/whoweare/transplantcenters.asp>, accessed July 12, 2009.

¹²See <http://optn.transplant.hrsa.gov/latestData/step2.asp>, accessed June 23, 2010.

¹³See <http://www.cms.hhs.gov/mcd/viewdecisionmemo>, accessed June 16, 2005.

¹⁴See <http://www.cms.hhs.gov/mcd/viewdecisionmemo>, accessed June 16, 2005.

¹⁵See <http://www.cms.hhs.gov/mcd/viewdecisionmemo>, accessed June 16, 2005.

patients with cancer that originated in the liver (hepatocellular carcinoma) improved with transplantation when specific medical conditions were met. Medicare coverage began for transplantation for eligible patients with certain liver cancers that year.¹⁶ Transplantation for liver cancer has grown steadily ever since. For patients ages 65 and over, 339 liver transplants were performed in 2001; in 2009, 697 were performed on older adults (up from 619 in 2008).

This broadening of the Medicare criteria for payment of lifesaving procedures can be read in at least two ways. Most simply, it is a testament to scientific progress in medicine. There is no doubt that liver diseases have slowly given way to treatments that save and prolong life. Secondly, Medicare is the vehicle that enables high-tech medicine to link notions of freedom and self-realization to longevity making. Because Medicare beneficiaries can “choose” life-extending treatments that will be paid for by the government, and because they can opt for “more” time and life, the enactment of Medicare policy is ethicality at work. By legitimating life-extending procedures for those in later life, by joining evidence with ethics, the world of longevity making is opened up. For physicians, that means offering and encouraging the use of life-sustaining treatments (as long as patients are deemed medically appropriate), because evidence indicates that they will save lives. For patients and families, that means the enormous responsibility for maintaining a delicate balance between advocating for too much or not enough intervention, for “ending” life too soon or carrying it on for too long.

Because it has come to include more diseases and treatments under its reimbursement umbrella, Medicare allows more people to fulfill both the desire for longer life and the expectation that medicine can cure more and more diseases. There is no doubt that many come to understand their bodies, lives, and futures—including the idea of normal lifespan—in terms of options for medical intervention that may extend life (Kaufman et al. 2006; Shim et al. 2007). Medicare, by constantly scrutinizing new clinical developments, creates both the infrastructure and value for this to happen. The difficulty of saying “no” to treatments that Medicare will pay for and that then are considered standard illustrates how deeply bound to each other the values of freedom, self-realization, and longevity making have become.¹⁷

Demographics, Disease Burden, and the Creation of Need

Because many diseases causing liver failure are age specific, and some are increasingly common in patients of advancing age, the number of older transplant candidates is substantial.

—Lipshutz and colleagues, *Archives of Surgery*, 2007

Liver transplantation is now the standard treatment for liver cancer and end-stage liver failure (Stamstein and Emond 2000). Who are getting liver transplants today and why? Improved medical management of cirrhosis has led to increased numbers of older people with chronic liver disease (Keswani et al. 2004; Lipshutz et al. 2007).¹⁸ Primary liver cancer is increasing, in large part because of the increased number of Americans who are chronically infected with hepatitis B virus (HBV) and hepatitis C virus (HCV).¹⁹ Both those

¹⁶See <http://www.cms.hhs.gov/mcd/viewdecisionmemo>, accessed June 16, 2005.

¹⁷Yet the taxpayer and government, together, carry the cost burden of these treatments. A patient I followed from 2007 to 2009 told me that his liver transplant at age 78 in 2008 cost nearly \$300,000. It was fully covered by Medicare. The aging of the population, disease patterns and greater need and desire, together, forecast greater cost burden. It remains to be seen whether that burden will dictate shifting patterns of governance and subjectivity. The government can choose not to fund certain procedures, but desire and expectation cannot be altered with a reimbursement decision.

¹⁸Cirrhosis is the death of liver cells and scarring of the liver.

¹⁹See <http://www.cdc.gov/hepatitis/B/bFAQ.htm#statistics>; <http://www.cdc.gov/hepatitis/C/cFAQ.htm#statistics>, accessed June 19, 2009.

viral infections put one at increased risk for liver cancer. With the availability of the vaccine for HBV, the incidence of that virus peaked in the mid-1980s. Although new incidence of HCV peaked in the United States in the late 1980s, approximately 1.3 percent of the total U.S. population is chronically infected with HCV, and cases have increased among those over age 40 (Morbidity and Mortality Weekly Report [MMWR] 2009). This high burden of HCV disease in the United States has made it the leading cause of liver disease (MMWR 2009).²⁰ One to five percent of persons with HCV will go on to develop cancer of the liver. And approximately half of liver transplants today are for HCV-related conditions.

Importantly for the Medicare program, the time from initial viral infection to complications from HCV, including cancer, is about 20–30 years. I observed two ways this long gestation period manifests in clinics. Some older patients have known about their HCV for many years, and they go to a specialized liver clinic periodically to have their conditions monitored. Others learn they have Hepatitis C or liver cancer from recent symptoms or blood work carried out by their primary physician for some other reason. Their doctors attribute many of their infections to blood products they had received for surgeries 20–30 years previously, before HCV was understood and before it could be detected in blood.

In patients infected 20–30 years ago, either mostly through blood products given before screening was available or through intravenous drug use, complications are now occurring. Because liver transplantation, during that same 20-year period, has shifted from “unthinkable” (Stamstein and Emond 2000) to standard therapy and, thus, to ethical necessity (Koenig 1988), the need for liver transplantation to avoid death is increasing as well.²¹

If current trends persist, by the year 2020 the majority of patients being evaluated for liver transplantation in the United States will be over the age of 70 because of HCV and other liver diseases (Cardenas and Gines 2008).²² Persons age 65 and older who have been coming to liver clinics for evaluation in the last decade or so constitute the leading edge of this trend. Because liver diseases such as HCV can be diagnosed and monitored before patients are too sick to undergo transplant surgery, because primary care physicians refer patients with liver disease to major centers for transplant evaluation, and because the size of cancer tumors can be controlled prior to transplantation, thus enabling transplantation to cure cancer before it spreads beyond the liver, actual transplantation becomes a more common and successful enterprise—the logical end point for liver cancer and other “end-stage” liver diseases.

The prowess of medicine to extend older lives, regardless of extent of disease, frailty or age, has become difficult if not impossible to refuse because its techniques are successful, Medicare pays for it, and broad expectations demand it. Within this ethical terrain the value of life is strongly linked to the amount of it, and technical ability is moral reason to proceed. Part 2 illustrates these points.

²⁰See <http://www.cdc.gov/hepatitis>, accessed June 19, 2009.

²¹HCV does cause liver inflammation and scarring, which can lead to liver cancer. The virus itself does not cause cancer. See http://www.medicinenet.com/liver_cancer/page2.htm, accessed June 19, 2009. The average time to develop primary liver cancer after initial exposure to HCV is about 28 years, and usually about 8–10 years after the development of liver cirrhosis (MMWR 2009). Thanks to Scott Biggins and Michael Thaler for clarifying these points.

²²Scott Biggins, personal communication, accessed June 9, 2009.

Part 2. Reflexive Longevity: The Effects of Governance on the Practice of Living

Physician recommendations, patient concerns, and the actions that result are the end product of this governance, already overdetermined. In the clinic we see how the weighing of options and obligations and the sensibilities brought to bear on that weighing are grounded in standard clinical pathways and logics of treatment. “Decisions” (whether proactively made or not) to follow one pathway or another through the health care system (or out of the system entirely) are the site at which obligation is made explicit, and they reveal the existential ground on which ethicality comes to rest.²³

I refer to that existential ground as *reflexive longevity*—the various sensibilities held by all the participants in the health care system about calculating, for example, whether and to what extent life can be prolonged by medical therapies (physicians); what the costs of that life extension might be in terms of quality of life and suffering (physicians, patients, families); how much more time is wanted (patients); and whether additional time is worth the effort, pain, and suffering of major medical interventions (patients and families). The term *reflexive longevity* instantiates a relentless, naturalized future-thinking about life itself, in which *longevity* has become an object of biotechnical intervention and a personal responsibility. *Reflexive longevity* emerges every day in clinics across the United States. It is evidence of the contemporary temporality described in the opening section of this article, in which the apprehension of risk and the malleability of the arc of human life become ever-present personal responsibilities and dominate self-awareness and moral choice.²⁴

Methods

This article results from an ethnographic project, begun in 2003, exploring the sociomedical and political economy developments surrounding the use of life-extending technologies among persons age 70 and above. The project explores the effects of medicine and health care structures and policy on the ways in which late life is approached and lived, and it interrogates the ways in which the demands of U.S. aging society for ever more intervention impact clinical practice, including what has become routine and naturalized about it. One project goal has been to describe how physicians, older persons, and their families enter into and understand the uses of a variety of treatments, all of which are on the rise for older persons in the United States—renal dialysis, cardiac surgeries, cardiac implantable devices, aggressive cancer treatments, and kidney and liver transplant. A second goal has been to explore the emergence and enactment of risk awareness and time management strategies in relation to those therapies and their potentiality for extending life when one is older. Finally, this project begins to map a phenomenology and practice of responsibility and obligation within the ethical contours framed by public and private health care finance mechanisms and their source in particular values, the technological imperative in medicine, and the implicit promises of biomedical research to “conquer death one disease at a time” (Callahan 2009b: 108).

²³I am indebted to Vincanne Adams for emphasizing this point.

²⁴My term, *reflexive longevity*, closely follows Giddens (1991), in his description of *reflexivity* as part of the modern condition. Giddens notes the following: that reflexivity refers to “chronic revision in the light of new information and knowledge” (1991:20); that reflexivity undermines the certainty of knowledge because doubt is always present; and that the awareness of lack of certainty is existentially troubling for individuals (1991:21), who must continually explore and construct an identity vis-à-vis social change (1991:33). Giddens notes that the self becomes a “reflexive project” (1991:32), ever aware of self-construction in the context of scientific discovery and new knowledge of all kinds (1991:33). My ethnography grounds Giddens’s theory in the empirical world of liver disease and clinical practice by illustrating the ways in which reflexivity is made manifest both for those in later life and for those who care for and about them.

The analysis reported here is based on data Kaufman collected between 2007–09 in a major medical center that draws from a multiethnic population and serves both urban and rural patients with different kinds (public, private, combination) of insurance coverage.²⁵ In the clinic setting I sat, first, with patients and families in waiting rooms and listened as they discussed their conditions, their fears and hopes about treatment and potential treatment, and their frustrations with the bureaucracy of scheduling diagnostic tests, receiving test results, and communicating with health providers. I heard them ponder the many “what ifs” associated with considering major interventions, especially a liver transplant: What if I choose not to have it? What if I don’t encourage my mother to go through with it? What will recovery mean for my older relative, for my ability to work? for care of my own family? What if he does not recover? Then, in the exam room, I observed members of the medical team (physicians, nurses, social workers) in discussions with patients and family members, and there I took handwritten notes of most things said. Those exam-room conversations lasted anywhere from 15 minutes to over an hour and covered some or all of the following topics: symptoms and symptom control; the course of the patient’s liver disease and what treatments were necessary to slow or stop it; the pros and cons of liver transplant; diagnostic test results and what those meant for further treatments; upcoming tests and continued disease surveillance; fears of surgery; reasons to prepare for transplant; patients’ shifting opinions about desire for or acquiescence to a transplant; and family member concerns about caregiving, death, and possible living liver donation.²⁶

Arrival at the Clinic: The Forms of Access

People arrive at major medical centers for evaluations of liver disease mostly from referrals made by their local doctors. For patients, self-screening and family support work in conjunction with physician referral. Engagement with the hope and complex treatment regimens offered in major medical centers requires a great deal of organization on the part of patients and families, including a proactive stance, social support that is visible to health providers, the energy and planning of getting to the center, and disciplined attention to paperwork and the timing of diagnostic tests and treatments. Patients who arrive at these clinics are mostly open minded, especially about life-prolonging, aggressive treatments. Or, their families have urged them to come.

Not all persons turned patients, perhaps especially those who are older, want to go or are capable of going this route. Because pathways of complex treatment weed out some, those patients and families who do arrive in major medical centers for extensive disease workup are, by and large, responsive to and compliant with all those things.²⁷ Most become quite knowledgeable about their diseases. Overall they are active citizens (Dean 1996:221) in their willingness and sometimes eagerness to engage the complexities (and discomforts) of diagnosis, treatment, and health care bureaucracy. Those are the kinds of patients I met. Most patients who return for continued treatment and evaluation agree, regardless of ambivalence, for their names to be placed on the national United Network for Organ Sharing

²⁵Those who come to major medical clinics for aggressive disease intervention are a self-selected group, and Medicare enables access to those treatments for those age 65 and above. Those were the kind of patients I met. Those who cannot access the clinic (and those who chose not to) were not part of this study.

²⁶I met 14 patients and 23 of their family members in clinics and observed their interactions with hepatologists, surgeons, nurses, and social workers. Of the patients, 7 were Euro-American, 1 was African American, 2 were Hispanic, and 4 were Asian (Chinese and Vietnamese). Of the patients, 9 were female, 5 were male. I conducted follow-up clinic visits, conversations, or interviews with all those patients or families until death (2), through the period of transplant surgery (3), disqualification from transplant eligibility (3), or up to 2010, as patients waited for their name to come to the top of the UNOS list. I interviewed 5 additional patients and 5 of their family members post-transplant. Of these patients, 2 had received livers from living donors; 4 were Euro-American, and 1 was Chinese American. Of the 19 patients followed, 18 were between the ages of 69 and 78 at the time of the transplant or clinic observation.

²⁷Thanks to Lakshmi Fjord for her insights about kinds of access.

(UNOS) waiting list for an organ,²⁸ if that seems necessary for their survival. Most of those agree to go ahead with transplant, if they are offered an organ.

Although Medicare ensures economic access for eligible citizens age 65 and over, and while patient and family commitment are essential, those two elements are only part of the access story. When health professionals consider transplantation for a patient, access is determined also by the scarcity and national regulation of organs. More than 15 thousand people awaited liver transplants in the United States in 2010 (all ages),²⁹ and only about 6,000 of them annually are able to access organs through UNOS. UNOS policies are occasionally revised to address the problem of fair distribution across geographic regions and allocation within regions (Keswani et al. 2004).³⁰ Thus, the older ethics of rationing exists alongside the ethicality I describe. Moreover, only older patients who give themselves “access”—through self-calculation about the worth of more time in relation to age and scarce resources—move forward toward liver transplant. Family and health professionals are part of that access endeavor. Patients who receive liver transplants are those whose families or health professionals envision a particular kind of future for them, and who encourage them along the routes of clinical surveillance and pretransplant treatment that are necessary prior to transplantation itself.

The Rationality of Treatment and Calculations about Time

Knowledge of disease and treatment guides clinical rationality and patient action. This has been true since medicine began curing and managing disease. Yet two factors mark the contemporary moment as different. First, health care policies and the evidence base on which they rest shape knowledge of the therapeutic (Rosenberg 2007) as we have seen. Second, scientific rationality has become also a “mode of obligation” (Dean 1996:224) to longevity making at ever-older ages. These factors constitute *the ethical* today. Older patients and their families learn to consider the worth of a (potentially) extended life in relation to the promises and expectations of interventions. The important point is this: “technological reason” (Lakoff and Collier 2004) and the existential sensibilities that occur, more and more in the United States and elsewhere, within ever-emerging, life-prolonging clinical pathways (Rose 2001; Shim et al. 2007). Longevity making becomes a form of life.

Three examples below illustrate what becomes thinkable as the best medicine, and how that understanding shapes a telos of living for patients and families. The first example highlights the physician’s evidence-based logic. The second points to the development of patient need within that logic. The third shows patient and family socialization to the normality of transplant and how reflexive longevity emerges for the physician, patient, and family. In these examples we see how the authority of Medicare policy and clinical wisdom become embedded in self-responsibility for longevity making.

1. Preparing Patients

Four years after a series of interferon treatments cured her of the Hepatitis C virus, Mrs. Ames, age 71, still had cirrhosis (scarring), which was worsening, and she had liver cancer. Mrs. Ames had proactively started the interferon treatments. Now, she noted, she was here because of the cancer, and she wanted a transplant. The liver specialist (hepatologist) explained.

²⁸UNOS is the national nonprofit organization that operates the U.S. organ-sharing system.

²⁹See <http://optn.transplant.hrsa.gov/latestData/step2.asp>, accessed January 7, 2010.

³⁰Because the scarcity of organs is greater in heavily populated metropolitan regions, patients there must become much sicker than those in rural areas while they wait to come to the top of the UNOS list. Age is not part of the scoring system.

You were very lucky to have gotten rid of the virus. It comes back after transplant if you haven't gotten rid of it completely, and there is still a small chance it could come back, even after transplant.³¹ Now you ask, "Why do I have to wait for a transplant if I have cancer?" The answer is because we can treat the cancer, keep it in check while you wait for a transplant according to UNOS criteria. You have to be monitored very carefully. CT scans every 3 months; chemoembolization [i.e., chemotherapy delivered by catheter directly into the liver tumors] if there are tumors. Our job is to put you in the best possible position for a transplant.

The doctor clarified how the various treatments for liver cancer were both maintenance therapy and an enabling technology, providing more people with access to liver transplant. His explanation reflects the technological reasoning that drives the treatment pathways and that emphasize preparation for transplant. He continued, "If you're not in [UNOS] criteria for transplant, we treat you until the tumors are knocked out, or reduced in size, so that you are in criteria. If you are in criteria, we put you on the list."

In the ensuing months, Mrs. Ames was listed for a transplant because she wanted one and her condition "fit" the Medicare coverage criteria for transplantation. She still had to wait for her name to come to the top of the UNOS list. In that waiting period (frequently 9–12 months), her cancer would have to be monitored and treated so it did not spread beyond the confines of the liver. If it did, it would no longer be treatable via transplantation according to the best evidence. Or, she could become sicker before she was allocated an organ. In that case her daughter, who had offered to donate part of her own liver, and whose offer was accepted by Mrs. Ames, would begin testing for donor appropriateness. The pathways of access and the clinical and payment enterprises organize clinician, patient, and family calculability about making longevity.

2. Patient Need and Family Burden

Mr. Carter, age 72 was very ill with advanced liver disease. He had been diagnosed with Hepatitis C 17 years before I met him and, several years before, had suffered through 42 of 48 weeks of interferon therapy. "Every week you continue, you become more invested in it. So though I was getting sicker and sicker, I was more deeply committed each week." He stopped when the side effects made him too ill to continue. The virus did not disappear.

In 2003, when he was having more symptoms of liver disease, he was sent to a major center and placed on the transplant list. "I knew that HCV could turn into liver failure.... At the time, my wife and I thought, what a great thing to have transplant as a possibility in your back pocket. Isn't this wonderful, if it should be necessary. It seemed so remote.... And I thought I was of the age where I may never need a transplant." But liver cancer developed, and he was diagnosed with two tumors "that would have disqualified me from having a transplant. So I had radio-frequency ablation, and three chemoembolizations, every couple of months, because the tumors kept growing. It was the only way I could get a transplant."³²

His wife recounted,

By 2008 he was getting more and more debilitated. Then they asked if Adam could find a living donor. And we would get into these awful arguments because first, he wouldn't send the living donor information packets to our relatives. I wrote to Adam's sister, and it's the only time she never replied. And then our daughter said

³¹That doctor later informed me that 25 percent of transplant patients who have HCV get cirrhosis 5–7 years after the transplant. In 5 percent of those patients, the HCV comes back very severely, killing the patient in the first year following transplant.

³²Radio-frequency ablation is high frequency electrical currents that create heat that destroys the abnormal cells. It is commonly used to treat cancers that originate in the liver.

she would be a living donor. And I thought, “oh my god, I cannot stand the thought of ...” I was so torn, so upset. We had such horrible arguments. Because Adam would say, “I want a liver.” And I said, “I don’t want both of you having—” it was hell! And then, of course, my daughter took forever to get her blood tested, and that was a very stressful time, and thank god, she wasn’t the right blood type.

Mr. Carter recalled, “It was pretty clear that I wasn’t going to take anything from a relative. What a decision—going to a relative and saying, ‘They’re gonna take half your liver, and it’s just as serious an operation for you as it is for me ... ‘How can you? It’s the most difficult thing.” His wife responded, “But you wanted one so desperately you would have taken from her.”

Mr. Carter felt, after years on the transplant waiting list and after so much debilitating preparatory treatment, that he deserved an organ. It was the only way he would survive. He worried he wouldn’t be considered strong enough, at age 72 with severe disease, to withstand the operation. But two weeks after our conversation, Mr. Carter received a deceased donor liver.

When one will die without a new liver, and the UNOS waiting list is long (and getting longer all the time), love is demonstrated when one offers a part of one’s organ to another. That has been the case since organ transplantation became routine. What is new here is the generational direction of offering and giving, asking and receiving in an aging society, when more persons in later life will need organs to survive (Kaufman et al. 2006).³³ What does it mean, then, if one does not make the offer? What does that do to a family? Age matters when we ponder the additional question: Where does responsibility for longevity making reside?

3. Reflexive Longevity in Process

Mrs. Dang’s daughters brought her, at age 72, to a major center liver clinic because her chronic liver disease was becoming more advanced and her local doctor suspected cancer as well. In three clinic visits, over an eight-month period, I saw the patient and family move from ambivalence about such a major intervention to acceptance of it—for Mrs. Dang to live.

At the first clinic visit, the surgeon guided the family to think about the future when he said that he thought Mrs. Dang would be “in good enough” shape to withstand the stress of transplant surgery. He urged the family to make a decision about moving forward. He said, “I think she would have a tough year and then she could live 9 to 15 years with no problems.” The liver specialist told the family, “She has enough problems with the cirrhosis that she should be put on the UNOS waiting list. It’s a good idea to do that now.” Mrs. Dang did not want a transplant.

As I walked the family out of the building, one of Mrs. Dang’s daughters said, “I need to ask my mother if she wants to live 10 more years.” This kind of statement is only thinkable because clinical evidence paved the way for Medicare coverage of liver transplants, which can cure lethal disease and extend life for years. The survival statistics are compelling. It would not be rational not to do it. The surgeon’s words, encouraging the patient and family to consider living 5, 10, 15 years longer without liver disease, inspired the daughter’s question, as though one could know the date of the end of one’s lifespan, and then add 10 years to it. The surgeon’s words positioned the family to consider an open-ended future for

³³I am aware of the large anthropological literature on kidney transplantation in the United States and elsewhere, but I do not engage that literature here.

Mrs. Dang, regardless of her age. The reasoning of the surgeon and the response of the family exemplify ethicality at work.

At the second clinic visit six months later, the liver specialist presented the family with the numbers: 10 percent of patients die in the first year; 90 percent survive at least three years. And he said, "I think she would benefit from a liver transplant." Both the numbers and his words reflect the clinical evidence. The family walked out of the clinic extremely ambivalent.

Two months later, Mrs. Dang had turned 73. While I sat with the family in the waiting room, the daughters explained they were burdened by the thought of transplant, worried that surgery would shorten her life. They were ambivalent because age mattered to them. Was it worth it at her age?

The concerns of Mrs. Dang's family are well founded. I learned from liver specialists outside their conversations with patients that about 30 percent of those who do survive a liver transplant have a range of complications, some of them quite serious. The normalcy of liver transplant is what is presented, and that normalcy becomes a normative expectation. Although the variability of actual outcomes and the degree of uncertainty may be mentioned, those topics are generally not emphasized in clinic conversations, and so they are mostly absent from patient and family calculations.

One of Mrs. Dang's daughters also pondered out loud a now-frequently debated question: "If you have cancer and decide not to treat it, is that suicide? I don't think so, but I wonder. If I think my mother shouldn't be listed for transplant, is that murder?" These reflections—in which families feel the moral weight of guilt and complicity, as though they could be "killing" or "saving" a loved one—are common. Families come to feel that the onus is entirely on them. Those reflections are a downstream effect of technological innovation and its legitimization, first by Medicare reimbursement, and then, by what becomes standard, ethical practice. Three doctors had by now advised Mrs. Dang to have the transplant and the daughters were inclined to follow that advice. Mrs. Dang said she didn't know what she would do, but she was not completely opposed to a transplant.

A few minutes later in the exam room, the doctor said, "I feel strongly that a transplant is the best chance to save her life. Mrs. Dang, at that point, said, "I've made up my mind. It's okay. I'll do it to live."

Thus, Mrs. Dang headed down the pathway toward liver transplant because standard clinical pathways, the logics of treatment and its reimbursement, and professional and familial obligation all led toward that outcome. The doctors were guided by clinical evidence and Medicare guidelines. The family's conversion to transplantation as a solution to the patient's cancer occurred through several means. The health professional talk over time, especially the words, "I think she would benefit from a transplant," made the patient and family more comfortable with the idea that transplant was appropriate and necessary to save life. It became the logical, right, and natural thing to do, the only path to take. *Logical*, because her disease would progress and be the cause of her death, perhaps quite soon, and transplant could cure the disease, preventing death. A great deal of evidence shows this to be the case. *Right*, because saving life is the highest priority and because it can be done as a matter of course within the U.S. health care delivery system. *Natural*, because the links among the political, economic, and clinical structures that shape the pathway to transplant are mostly not seen by participants in the system.

Technological reason shapes the transplant subject, and the organization of the clinic guides how to live. Both Mrs. Ames and Mr. Carter, after years of "living in prognosis" (Jain 2007)

—fighting disease and aware that cirrhosis and cancer would eventually lead to liver failure and death—came to want the definitively curative treatment. They prepared for transplant with the required treatments to shrink their cancer tumors. They considered living donors. In the case of Mrs. Dang, the physicians' calculus about risk of death without a transplant and chances for survival with a transplant became the reason for her to go forward and reason for her daughters to support her decision. Inseparable from life-prolonging treatments are the burdens on families. The placement, or, indeed, offloading of ethical responsibility onto families is part of *the ethical*, though it is not part of the “evidence base” that guides treatment decisions. The Carter family was guided to consider a living donor; Mrs. Dang's children pondered the ethical ramifications of supporting or opposing transplant surgery. Their quandaries, common today, are largely erased from the cultural conversation about health care delivery and reform. For patients and their families, the political–economic–clinical enterprise works on and through understandings of “ordinary” aging and standard medicine to shape calculability about life.

Discussion and Conclusion

I have illustrated the contours of longevity making through a form of governance I term *ethicality*, in which ethical understandings of and responses to what is at stake in prolonging older lives are embedded in and formulated and organized through: the ever-emerging evidence for the “good” of technological intervention; the scientific discoveries, industry pressures, and payment policies, which, together, support and enable that “good”; and the resulting knowledge and sensibilities of doctors, patients, and families about calculating the worth of more time in light of always possible life-extending therapies.

Ethicality, I noted, stands on the shoulders of earlier conceptions of *bioethics*, which emerged from philosophy and theology (Jonsen 1998) and emphasized the doctor–patient dyad and individual choice, especially in the context of advanced technologies and limited distribution of resources. My notion of *ethicality* joins more recent explorations of *the ethical* by anthropologists and sociologists, whose work, taken together, has considerably broadened the scope of what constitutes the ethical and ethical problems.³⁴ Similar to other social scientists' expanded frames of ethical analysis,³⁵ I view financial, institutional, and government regulatory structures as central actors in organizing ethical norms, which then shape societal understandings of the right thing to do. And, I have traced the impacts of political–economic structures on the ways in which the logics of care are implemented and on the ways in which they resonate existentially among patients and families.

I draw attention to the ways in which *the ethical* runs through all aspects of the contemporary U.S. health care enterprise—from its source in scientific and industry invention, to the norms for clinical trial and other evidence that show treatment efficacy, to the policies that enable payment for therapies and then foster the understanding of those therapies as standard and routine. I show, as well, that those interventions become ethically necessary, so that physician, patient, and family deliberation and decision making all come to be framed through that necessity.

I emphasize Medicare coverage decisions because they serve as a foundational driver of this ethicality, shaping standard care, ethical necessity, and, thus, individual obligations and

³⁴Recent investigations have focused on, for example: the growing health and health care delivery disparities between rich and poor and the contributions of the rising costs of health care and the globalized, neoliberal markets to those disparities; the power of the multinational pharmaceutical industry to control clinical research agendas and the delivery of medical care in the developing world; the commodification of the body and body parts; the constitution of ethics within and the ethical problems created through the international biomedical research enterprise; and the regulatory and institutional practices surrounding new genetic technologies.

³⁵See especially De Vries and colleagues 2007, Petryna 2009, and Petryna and colleagues 2006.

quandaries about what needs to be done, what should be done. Medicare coverage decisions emerge from committees working through the CMS who sift through published and unpublished studies, clinical guidelines, technology assessments, recommendations from the Medicare Coverage Advisory Committee, expert opinion, and public commentary (Mendelson and Carino 2005) to arrive at benefits policies for specific treatments for particular conditions. Those coverage decisions about which treatments are safe, efficacious, and worthy of reimbursement both influence and respond to the technological imperative. In doing so, they further entrench the ethical necessity of extending ever-older lives with complex and expensive interventions—interventions that ask a great deal from patients, in terms of clinical surveillance and participation, and demand much from families, in terms of both caregiving and the responsibility for what they interpret as either facilitating life extension or bringing on unnecessary death.

Physician, patient, and family deliberation and “decision making”—the most “downstream” activity, or end product, in this terrain of governance—is prefigured, organized by Medicare policy itself. This is one of the ironic features of U.S. health care delivery today. The institution of Medicare, which governs access to treatments for older citizens and pays for state-of-the-art therapies, which expands coverage in response to ever-emerging science and evidence, also shapes health provider and consumer thinking that death is not and should not be inevitable right now. It shapes, thus, the downstream anguish and guilt associated with saying “no” to (always) potentially life-extending therapies and, therefore, makes saying “no” a difficult proposition.

This article makes this form of ethics explicit through the example of liver diseases and the expanding use of liver transplantation for them. Ethicality resides in the relationship among: medical knowledge about liver disease and treatment; the multiple imperatives to prolong life (technological, subspecialty, evidence-based, patient need, and advocacy) that arise from and with that knowledge; expanding policies for payment; and the easily normalized clinical practices, including transplantation, in which practitioners guide the conduct of sometimes ambivalent, sometimes eager but mostly willing patients. Ethicality is thus a diffuse and deeply rooted phenomenon, which impacts, ultimately, the conduct of individual lives, societal expectations about how to grow old, the meaning of family responsibility, and the U.S. economy.

This form of governance is naturalized, and so the linkages of value and economics among research, industry, policy, practice, standards, and necessity, which structure its formation, are largely invisible. Moreover, its various cultural effects—the ways medicine materializes time, the connections among each patient’s life and an open-ended future, and the enfolding of policy and clinical practice with the framing of responsibility and self-making—remain largely hidden from scrutiny as well.

In medicine the technical has become the ethical because contemporary medicine can so easily be brought to bear on extending precious lives. My example specifies this connection by revealing how the technical, in concert with the political-economic, becomes the ethical in the realm of ever-expanding longevity making in an aging society. The institution of Medicare—which instantiates an important social good through its commitment to health care services for older citizens, and sets standards of reimbursement for the private insurance industry—encourages, through the payment of ever more expensive technologies for an aging population, the notion that all diseases can eventually come under its coverage purview. It encourages the idea that more and more life-threatening and end-stage diseases can be—and should be—treated, made chronic, rather than end stage. In that way more citizens can envision and move toward open-ended futures.

The expansion in payment for ever more sophisticated and aggressive interventions has become the ethical norm. Yet this norm may be the undoing of Medicare because the costs of high-tech treatments to more and more older persons simply cannot be economically supported. The case study of liver disease and transplant is only one example of this ethicality at work. Aggressive cancer treatments, cardiac implantable devices, and surgical procedures of many kinds contribute to the broadening expectation that greater longevity in an aging society can always be achieved. Those interventions contribute, as well, to the high costs of health care delivery, which threaten the future existence of the Medicare Program. Because it is embedded in structures of rationality, values, evidence and health policy, the making of longevity in U.S. society—as a pervasive activity and societal goal—cannot be undone easily. This ethicality has broad societal consequences. And, it is a quintessential example of contemporary temporality at work.

Acknowledgments

The research on which this article is based was funded by the National Institute on Aging, grant RO1AG2846, to Sharon R. Kaufman, Principal Investigator. It received UCSF IRB approval. I thank the health professionals, patients, and families who welcomed interviews and allowed observations of clinic visits in 2008–09, and who spoke candidly about health care delivery, medical conditions, and treatment decisions. Many thanks to Vincanne Adams, Deborah Gordon, and Sarah Horton for their critical engagement of earlier drafts and to Lakshmi Fjord for her research collaboration. Mark Luborsky, Andrea Sankar, and two anonymous reviewers made thoughtful suggestions that helped shape the final version.

References Cited

- Adams, Vincanne; Murphy, Michelle; Clarke, Adele E. Anticipation: Technoscience, Life, Affect, Temporality. *Subjectivity*. 2009; 28:246–265.
- Bach PB. Limits on Medicare's Ability to Control Rising Spending on Cancer Drugs. *New England Journal of Medicine*. 2009; 360(6):626–633. [PubMed: 19176475]
- Beck, Ulrich. *Risk Society*. London: Sage; 1992.
- Becker, Gay. The Uninsured and the Politics of Containment in U.S. Health Care. *Medical Anthropology*. 2007; 26(4):299–322. [PubMed: 17943602]
- Bosk, Charles L. Professional Ethicist Available: Logical, Secular, Friendly. *Daedalus*. Proceedings of the American Academy of Arts and Sciences. 1999; 128(4):47–68.
- Burchell, Graham. Liberal Government and Techniques of the Self. In: Barry, Andrew; Osborne, Thomas; Rose, Nikolas, editors. *Foucault and Political Reason*. Chicago: University of Chicago Press; 1996. p. 37–64.
- Callahan, Daniel. Taming the Beloved Beast. Princeton: Princeton University Press; 2009a.
- Callahan, Daniel. Death, Mourning, and Medical Progress. *Perspectives in Biology and Medicine*. 2009b; 52(1):103–115. [PubMed: 19168948]
- Cárdenas, Andres; Ginès, Pere. Predicting Mortality in Cirrhosis. *New England Journal of Medicine*. 2008; 359(10):1060–1062. [PubMed: 18768952]
- Crawford, Robert. Health as a Meaningful Social Practice. *Health*. 2006; 10(4):401–420. [PubMed: 16973678]
- Dean, Mitchell. Foucault, Government and the Enfolding of Authority. In: Barry, Andrew; Osborne, Thomas; Rose, Nikolas, editors. *Foucault and Political Reason*. Chicago: University of Chicago Press; 1996. p. 209–230.
- De Vries, Raymond; Turner, Leigh; Orfali, Kristina; Bosk, Charles L., editors. *The View from Here: Bioethics and the Social Sciences*. Malden, MA: Blackwell; 2007.
- Fassin, Didier. Another Politics of Life Is Possible. *Theory, Culture and Society*. 2009; 26(5):44–60.
- Foucault, Michel. Governmentality. In: Burchell, Graham; Gordon, Colin; Miller, Peter, editors. *The Foucault Effect*. Chicago: University of Chicago Press; 1991. p. 87–104.
- Fox, Renee. The Evolution of American Bioethics. In: Weisz, George, editor. *Social Science Perspectives on Medical Ethics*. Philadelphia: University of Pennsylvania Press; 1991. p. 201–217.

- Fox, Renee. Is Medical Education Asking too Much of Bioethics? *Daedalus*. Proceedings of the American Academy of Arts and Sciences. 1999; 128(4):1–25.
- Giddens, Anthony. *Modernity and Self-Identity*. Stanford: Stanford University Press; 1991.
- Gillick, Muriel R. The Technological Imperative and the Battle for the Hearts of America. *Perspectives in Biology and Medicine*. 2007; 50(2):276–294. [PubMed: 17468543]
- Good, Byron J. *Medicine, Rationality and Experience*. New York: Cambridge University Press; 1994.
- Guyer, Jane I. Prophecy and the Near Future. *American Ethnologist*. 2007; 34(3):409–421.
- Hlatky, Mark A. Evidence-Based Use of Cardiac Procedures and Devices. *New England Journal of Medicine*. 2004; 350(21):2126–2128. [PubMed: 15152058]
- Hoffmaster, Barry, editor. *Bioethics in Context*. Philadelphia: Temple University Press; 2001.
- Jain, Sarah Lochlann. Living in Prognosis. *Representations*. 2007; 98(1):77–92.
- Jonsen, Albert R. *The Birth of Bioethics*. New York: Oxford University Press; 1998.
- Kaufman, Sharon R.; Russ, Ann J.; Shim, Janet K. Aged Bodies and Kinship Matters: The Ethical Field of Kidney Transplant. *American Ethnologist*. 2006; 33(1):81–99. [PubMed: 18461150]
- Keswani, Rajesh; Ahmed, Aijaz; Keefe, Emmet B. Older Age and Liver Transplantation: A Review. *Liver Transplantation*. 2004; 10(8):957–967. [PubMed: 15390320]
- Koenig, Barbara A. The Technological Imperative in Medical Practice. In: Lock, Margaret; Gordon, Deborah, editors. *Biomedicine Examined*. Boston: Kluwer; 1988. p. 465–496.
- Lakoff, Andrew; Collier, Stephen J. Ethics and the Anthropology of Modern Reason. *Anthropological Theory*. 2004; 4(4):419–434.
- Lipshutz, Gerald S.; Hiatt, Jonathan; Ghobrial, R Mark; Farmer, Douglas G.; Martinez, Monica M.; Yersiz, Hasan; Gornbein, Jeffrey; Busutil, Ronald W. Outcome of Liver Transplantation in Septuagenarians. *Archives of Surgery*. 2007; 142(8):775–784. [PubMed: 17709732]
- Mendelson, Dan; Carino, Tanisha V. Evidence-Based Medicine in the United States. *Health Affairs*. 2005; 24(1):133–136. [PubMed: 15647224]
- Miller, Philip Lee. *The Life Extension Revolution: The New Science of Growing Older without Aging*. New York: Bantam; 2006.
- Morbidity and Mortality Weekly Report (MMWR). [accessed June 19, 2009] Surveillance for Acute Viral Hepatitis, United States 2007. Surveillance Summaries May 22. 2009. 58/No.SS–3. <http://www.cdc.gov/mmwr>
- Neumann PJ, Rosen AB, Weinstein MC. Medicare and Cost-Effectiveness Analysis. *New England Journal of Medicine*. 2005; 353(14):1516–1522. [PubMed: 16207857]
- Petryna, Adriana. *When Experiments Travel: Clinical Trials and the Global Search for Human Subjects*. Princeton: Princeton University Press; 2009.
- Petryna, Adriana; Lakoff, Andrew; Kleinman, Arthur, editors. *Global Pharmaceuticals: Ethics, Markets, Practices*. Durham, NC: Duke University Press; 2006.
- President's Council on Bioethics. [accessed October 24] Beyond Therapy: Biotechnology and the Pursuit of Happiness. 2003. <http://www.bioethics.gov/reports/beyondtherapy>
- Rose, Nikolas. Governing “Advanced” Liberal Democracies. In: Barry, Andrew; Osborne, Thomas; Rose, Nikolas, editors. *Foucault and Political Reason*. Chicago: University of Chicago Press; 1996. p. 37–64.
- Rose, Nikolas. *The Politics of Life Itself. Theory, Culture and Society*. 2001; 18(6):1–30.
- Rose, Nikolas. *The Politics of Life Itself*. Princeton: Princeton University Press; 2007.
- Rosenberg, Charles E. *Our Present Complaint*. Baltimore: Johns Hopkins University Press; 2007.
- Shim, Janet K.; Russ, Ann J.; Kaufman, Sharon R. Clinical Life. *Health*. 2007; 11(2):245–264. [PubMed: 17344274]
- Shore, Cris; Wright, Susan. Policy: A New Field of Anthropology. In: Shore, Cris; Wright, Susan, editors. *Anthropology of Policy: Critical Perspectives on Governance and Power*. New York: Routledge; 2007. p. 3–39.
- Stamstein, Benjamin; Emond, Jean. Liver Transplants from Living Related Donors. *Annual Review of Medicine*. 2000; 52:147–160.

- Tunis, Sean R. Why Medicare Has Not Established Criteria for Coverage Decisions. *New England Journal of Medicine*. 2004; 350(21):2196–2198. [PubMed: 15152066]
- Wilk, Richard. It's About Time. *American Ethnologist*. 2007; 34(3):440–443.

\$watermark-text

\$watermark-text

\$watermark-text