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Making Longevity in an Aging Society:

Linking Medicare policy and the new ethical field

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Abstract

Life-extending interventions for older persons are changing medical knowledge and societal expectations about longevity. Today's consciousness about growing older is partly shaped by a new form of ethics, constituted by and enabled through the routines and institutions that comprise ordinary clinical care. Unlike bioethics, whose emphasis is on clinical decision-making in individual situations, this new form of ethics is exceptionally diffuse and can be characterized as an *ethical field*. It is located in and shaped by health-care policies, standard technologies, and clinical evidence, and it emerges in what patients and families come to need and want. Three developments illustrate this ethical field at work: the changing nature of disease, especially the ascent of risk awareness and risk-based strategies for life extension; the role of technology in reshaping the ends of medicine; and the role of Medicare policy in creating need and ethical necessity. Medicare's expanding criteria for payment coverage of liver transplantation and implantable cardiac devices illustrate the pervasive logic of this new form of ethics. The powerful connection between the technological imperative and its ethical necessity is rarely mentioned in Medicare reform debates.

An explosion in the varieties of life-extending interventions for older persons is changing the face of many medical specialties in the United States, altering the nature of end-stage disease, and reshaping societal expectations about normal old age, longevity, and the time for death. There is no doubt that the rapid growth of the over-85 age group and better health in late life for many people in the United States are redefining "old." Robert Butler, founding director of the National Institute on Aging, has stated that "80 is the new 60," adding to other popular remarks that signify a changed understanding of life course expectations, especially for those who can access all that medicine has to offer. Overall, practitioners and health-care consumers alike consider the body malleable, treatable at any age (President's Council on Bioethics 2003). These developments are influencing patient, family, and medical responsibility in ways that could not have been predicted even a decade ago.

The growing array of life-extending therapies, together with the ratcheting up of the age for treatments, has intensified the already recalcitrant and well-known tension between the desire and the ability to cure disease and extend life by any means on the one hand, and the widespread societal cry in the United States to resist interventions that prolong dying and suffering on the other. That tension is becoming more deeply entrenched, because when patients and their families are faced with life-threatening disease and told by their doctors that they may benefit from certain treatments (even if the chances are small), it is difficult to say "no." And why would they? To reject therapies that are quickly becoming the standard of care would be to deny medicine's progress in curing and preventing disease, the scientific context of clinical practice, and the assumption that doctors are considering what is best for

this patient—an individual with a particular constellation of diseases, symptoms, and functional abilities.

A New Ethical Field

Notions of aging are mutable of course, grounded in historical moments, cultural innovation, and social norms. Today's consciousness about growing older is partly shaped by a new form of ethics that can be distinguished from bioethics, which emphasizes clinical decision-making in individual situations. This new form of ethics is exceptionally diffuse and therefore difficult to discern. It is located in and shaped by health-care policies, standard and emerging technologies, and the clinical evidence that supports technology use. It is constituted by what patients and families come to need and want, which I illustrate below. Ultimately, it emerges in the physical care-giving tasks and emotional burdens placed on families. Its logic and routines permeate every aspect of health-care delivery and affect everyone: clinicians, patients, and families alike. Though relatively new, this ethical field has already become, like the air we breathe, mostly unnoticed.

This new form of ethics stands on the shoulders of, and displaces, earlier concerns of bioethics—such as the committee debates, beginning in the early 1960s, about rationing kidney dialysis to “deserving” citizens, and the concern, beginning in the 1970s with Karen Quinlan, about who can withdraw life-sustaining treatment from whom, and when (Jonsen 1998). While those issues—of allocation, selection, and responsibility for life and death—certainly linger (and the 2005 case of Terry Schiavo is illustrative), a different pattern is now emerging, in which 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.

My first task as an anthropologist is to trace the sources and effects of this new ethical field so that its diffuse locations in American institutions, technological developments, and clinical practice can be better understood, and my second is to analyze the ways in which the socio-ethical changes taking place in the delivery of medical care are affecting ordinary medicine and the quality of individual experience. On the way, I nod toward some of the difficult issues facing health-care delivery today, especially new technologies and their open-ended use, and a few of the ways in which age does and does not matter. I also touch on what gets minimized and erased from clinical and policy discussions in the lure of life-extending treatments.

The Ethical Field at Work

At least three developments illustrate the new ethical field at work: the changing nature of disease; the role of technology; and the role of Medicare policy.

Changing Nature of Disease

In *The Longevity Revolution* (2008), Butler notes that disease is “a fluid concept influenced by societal and cultural attitudes that change with time and in response to new scientific and medical discoveries” (p. 88). Adding to this definition, Charles Rosenberg (2007) argues that because of “changes in the evaluation of clinical evidence, in government policy and in the public negotiation of diagnostic and treatment standards . . . Disease has become a bureaucratic—and thus, social and administrative—as well as biological and conceptual—entity” (p. 5). This ethnographic essay explores the ramifications of Rosenberg's insight.

In the context of policy, bureaucracy, and shifting standards of evaluation, ideas about disease change with scientific discovery and emerging diagnostic capability. Today a wide

array of diagnostic tests enable ever-more finely tuned understandings of bodily conditions, which lead, in turn, to ever-more interventions. Doctors, patients, and the public learn to understand what counts as health, disease, and standard medical care in terms of diagnostic and treatment pathways. Then, what counts as risks of disease and benefits of treatment naturally follows.

More broadly, patients and practitioners alike have come to think about the truths of the body—and of life itself—in terms of numbers, scores, and scans. Blood pressure and cholesterol measurement, prostate specific antigen test numbers, kidney creatinine levels, cardiac ejection fractions, stages of cancer, white blood counts, and liver function scores, for example, are all representations that have enabled us to understand the extent of disease and degree of health. These diagnostic numbers have come to matter to us. They were not always there. We organize behaviors, engage treatments, undertake the care of others, and consider risk and the future in terms of those representations. The ubiquity of diagnostic tests and their numerical results have led us to understand that it is the patient's responsibility to do something about those results, and that it is the physician's responsibility to point out where and why.

Social theorists Ulrich Beck (1992) and Anthony Giddens (1991) have described the ways in which risk as a way of knowing and risk assessment as a technique for living constitute the structural conditions of life in postindustrial society. They and others stress the ways in which strategies for living and life planning are open to continual revision and how those strategies, more and more often, emphasize the relationship between identity and “the biological” (Giddens 1991; Rose 2007). Health risks have come to take center stage through new knowledge about the genome, the environment, food, and so forth. Foundational to longevity-making is the idea that risk and responsibility for health have come to be seen as located within individual bodies and lives (Beck 1992; Crawford 2006). There is no doubt that risk awareness drives much health-care delivery today, and that awareness has altered the way disease is understood. Indeed, personal responsibility today consists largely of awareness of health risk and disease prevention strategies. One response to that sensibility is what Kathleen Woodward (1999) calls “statistical panic”—the anxiety resulting from the ways in which our “society of statistics” provokes panic by engaging the experience of always being at risk, mostly through knowing the numerical scores of our corporeal conditions.

Role of Technology

The second development illustrating the diffuse location of the new ethical field is the role of technology. For clinicians, the unavoidable “technological imperative” in medicine, first described by health economist Victor Fuchs (1974), becomes, also, a moral imperative. Anthropologist Barbara Koenig (1998) pointed this out more than two decades ago, showing that the shift in meaning occurs because new technologies almost immediately “feel” routine to practitioners and then quickly become standard of care. “Once a new technology is developed,” she noted, “the forces favoring its adoption and continued use as a standard therapy are formidable” (p. 467). “Standard of care becomes a moral, as well as technical, obligation,” she wrote, and it is exceptionally difficult for clinicians, and then patients and families, to refuse. In the culture of medicine today, the technological imperative is bolstered by the value given to evidence-based studies. And technical ability (via drugs, devices, and procedures) becomes ethical necessity. Patients and families, like health providers, understand today's technologies as ethically necessary and think of them, as well, within the parameters of risk awareness and reduction that characterize so much activity in health-care delivery and in life.

Within the broad scheme of diagnostic capacity and risk awareness, an ethical demand emerges in which patient and family consideration of the value of life is strongly linked to the amount of it perceived to be remaining, and technical ability becomes reason to proceed. Successful outcome percentages for many procedures deepen the “ethical good” of this development. For all players, as the risks associated with different technologies diminish—cardiac surgeries and organ transplantation are good examples—the social and medical perception of risk shifts to the risks of death—and doing everything possible to reduce those risks (Fleck 2009).

In exploring the relationship between technology and morality, Latour and Venn point out the ways in which technologies of all kinds are not merely means to specific ends, and they shows that “ends” are not static and already known (Latour and Venn 2002). Rather, they describes how we change the ends as new means emerge and develop—and biomedical technologies are good examples of this phenomenon: “If we fail to recognize how much the use of a technique, however simple, has displaced, translated, modified, or inflected the initial intention, it is simply because we have *changed the end in changing the means*, and because, through a slipping of the will, we have begun to wish something quite else from what we at first desired” (p. 252). Technologies, they argue, are never merely instruments, utensils fulfilling a predetermined function. Rather, they are a form of mediation—between intention and the discovery of multiple functions not foreseen, and between original plans and their inevitable mutations. Thus while specific tools may in fact fulfill one intended purpose, they also, and perhaps more importantly, incite new ways of thinking about the kinds of ends we may desire.

Role of Medicare Policy

The third development illustrating this new ethical field is the role of Medicare policy in determining appropriate practice and ethical necessity. Medicare, which influences coverage decisions among private insurers, is essential background to what becomes standard of care medical practice. Committees working through the Centers for Medicare and Medicaid Services (CMS), which administers the Medicare program, continually review and 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). Because treatments for life-threatening cancers, cardiac diseases, and other conditions are common among the elderly, Medicare policies become fundamental to how life is lived for a growing segment of the population.

The process by which treatment coverage is decided is dynamic because different kinds of factors contribute to it: new discoveries in the laboratory; clinical trials results and other evidence-based outcomes data; and pressures brought from the U.S. Congress, physician lobbying groups, proactive consumers, the device and pharmaceutical industries, and the private insurance industry. Yet 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. Materials scrutinized by the CMS include published and unpublished studies, clinical guidelines and clinical trials, technology assessments, recommendations from the Medicare Coverage Advisory Committee, and other expert opinion (Mendelson and Carino 2005). Importantly, series of clinical trials that show benefit for use of a specific procedure or device increase the pressure on Medicare and other large payers to expand coverage (Hlatky 2004).

At its most basic, Medicare is an ethical program, in the sense that it provides state-sponsored health services for any older citizen. That part is obvious. But more than that, Medicare coverage decisions legitimate certain life-extending treatments and allow for the allocation of resources, some of them extremely scarce, to specific groups. Those decisions

embody values and priorities about the kinds of structures of health-care delivery the state should support (such as transplant centers and the many research and clinical enterprises that flow to and from them), and also about which therapies are worth covering for a group of patients, and for which conditions. By not paying for certain treatments, Medicare also rations. Thus it is implicated, at its core, in the ethics of managing life. It is useful to think of Medicare as a tool that facilitates the ever-expanding use of life-extending procedures, a tool through which the U.S. government and American taxpayers, together, shape the conduct of longevity-making for themselves and their loved ones.

The lack of attention paid by the CMS to cost-effectiveness and the inability to define value in relation to specific interventions and outcomes (Cortese and Korsmo 2009; Tunis 2004)—two areas central to current Medicare reform debates—highlight the fact that the technological imperative, rather than value in relation to costs and outcome, is at the root of the ethics of Medicare policy.

The Ethical Effects of Medicare Coverage Decisions

The individual ethical decision-making that takes place downstream in clinics, by individual patients, families, and physicians—and which has been the focus of clinical bioethics—is thus already prefigured by Medicare coverage policies and, importantly, by the kinds of evidence on which those policies rest. Clinical trial evidence privileges new technologies (drugs, devices, procedures) that then shape what becomes standard therapies. Those, in turn, create need and ethical necessity. Cost-effectiveness and value (for any one patient and for society) are ignored or minimized in this constitution of the ethical.

By enabling payment for new treatments, by legitimating life-extending procedures for those in ever-later life, and by joining technological evidence with ethics, Medicare coverage decisions (along with private insurance) open up the world of U.S. longevity-making. This includes decisions by universities and hospitals to hire the best surgeons and to purchase expensive equipment so they can participate in state-of-the-art diagnosis and treatment, thereby attracting patients and referrals by doctors. For physicians, that means offering and often encouraging the use of life-sustaining treatments, at any age and any cost, because evidence indicates they will prolong life. For patients and families, the world of longevity-making carries with it the responsibility of pursuing the right amount of treatment—that is, for walking the perilous line between doing too much (thus prolonging dying) and not doing enough (rejecting therapies that might extend quality life). Medicare, by enfolded the logic of evidence-based therapeutics into its coverage policies, creates both the infrastructure and the value for the linkages among need, ethics, and longevity-making to occur. This feature of Medicare ethics is absent from public debate.

The Emergence of Need

Two recent examples of therapies that have shifted from “unthinkable” even a decade ago to routine and standard treatments for Medicare-eligible individuals today are liver transplantation for primary liver cancer and the expanding use of the implantable cardiac devices. “Need” for any individual patient (and family) emerges in dialogue with physicians and other health professionals, but it is established by standard treatments. One cannot “need” a therapy that has not been proven effective. Examples from my ethnographic research illustrate the emergence of need, first in the case of liver transplantation and then in the case of the implantable cardiac devices. These examples show that need, standardization, clinical appropriateness, and ethical necessity have become inextricable. Those entanglements drive and give shape to longevity-making.

Organ Transplantation

Over time, Medicare policy has broadened the eligibility criteria for liver transplantation so that for persons age 65 and beyond, previously fatal liver diseases are now treatable. Medicare began payments to hospitals for liver transplants in 1991, but only for a limited number of diagnoses. By 2001, studies showed that outcomes for patients with hepatocellular carcinoma improved with transplantation when specific medical conditions were met. Medicare coverage for certain eligible patients began that year. Transplantation for liver cancer has grown steadily ever since, and there is no doubt that it prolongs lives. Overall, liver transplants are the second most common organ transplant operation (after kidneys) in the United States. They are performed in 127 American centers. More than 6,300 (6,319) liver transplants were performed in 2008, 10% of them (619) on older adults, up from 339 liver transplants on older adults in 2001 (OPTN 2009). Older patients I met in different centers in the United States who were candidates for transplant, or who had received transplants, may be considered the leading edge of these numbers, because many liver diseases that begin earlier in life, such as hepatitis C, take years to become end-stage, and so it is older adults who “naturally” come to need a transplant to survive. In an aging society, more older persons will come to need liver transplants in the years ahead. The important point is that this therapy—transplantation—becomes ethically necessary to avoid death.

The determinative link between Medicare approval and standard of care is the crux of the matter here, because standard of care means appropriate practice. Medicare does not provide payment for treatments in which the evidence base is weak, but it does, eventually, provide coverage for an intervention when enough evidence accumulates to show treatment efficacy. In this way, Medicare coverage decisions authorize best practices through the acknowledgment that the evidence produced in clinical trials or in outcome studies is now scientifically adequate to show safety and positive outcomes. Coverage decisions are, in fact, ethical priorities, because access, health, and survival are at stake.

How Age Matters

From a societal point of view, age matters when ever-larger numbers of persons become Medicare eligible for procedures, because the conflicts between cost and social justice and between allocation and scarcity intensify. But in tension with those societal issues is the fact that today, published evidence in medicine, along with societal values, stress that age does not matter in the clinic where many procedures, such as the ICD and liver transplant, have been shown to successfully prolong the lives of older persons (Chan et al. 2009; Lipshutz et al. 2007). In those and many other studies, advanced age per se does not indicate ineffectiveness of the therapy. Geriatricians and other specialists know this well. Yet there is no question that age matters at the “user” end, when treatments that become part of the standard repertoire of clinical practice open up questions that have plagued bioethics, geriatrics, and some of the high-tech medical and surgical specialties for at least two decades—that is, whether and how long to pursue longevity-making.

The Case of Mrs. Dang: The Logic of Transplantation

Mrs. Dang, age 73, came to a major liver clinic with her daughters because her doctor thought she might have liver cancer. When cancer was diagnosed there, the liver specialist asked Mrs. Dang, “Do you want a liver transplant?” He continued, “10% of patients die in the first year; 90% do well; though 30% have complications. You have two problems, advanced liver disease and cancer. I think you would benefit from a liver transplant. You are eligible for a transplant” (meaning that the treatment for her condition would be reimbursable by Medicare).

The surgeon arrived for the consultation and guided the family toward the future when he said Mrs. Dang was in “good enough” shape to withstand the stress of transplant surgery. He said, “If things go well, she could live five, 10, or even 15 years.” Mrs. Dang responded, “I’m scared. I don’t want it.” As I walked with the family out of the clinic building, one of Mrs. Dang’s daughters said, “I need to ask my mother if she wants to live 10 more years.” This remark is only “thinkable” because clinical evidence paved the way for Medicare coverage of liver transplants, which can cure lethal disease and extend life. The survival statistics are compelling. The surgeon’s evidence, encouraging the patient and family to consider living five, 10, 15 years longer without liver disease, inspired the daughter’s question and positioned the family to consider an open-ended future for Mrs. Dang, as though that “added” time would naturally result from treatment.

In the waiting room several months later, the daughters explained that they had not discussed “which way” they or their mother “wanted to go,” that is, whether or not to pursue a transplant. They worried that the surgery would not prolong her life, but rather shorten it. They were ambivalent because age mattered to them. Was it worth it at her age? Their worries were part of the emotional work and ethical responsibility that have been transferred to families as they respond to the prospect of potentially life-extending interventions, as they respond to the technological imperative and the value placed on clinical evidence. Families’ worries are often not raised in the clinic, because the lure of the evidence for life extension is so powerful. The responsibilities that rest on their shoulders thus often remain invisible to clinicians, and they are erased from the cultural conversation about reform.

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 a huge moral burden 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. 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 reported new information, saying, “She has two lesions, not just one. I feel strongly that a transplant is the best chance to save her life. The odds are that she’s not going to live very long without it.” 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 everyone wanted her to survive. The doctors were guided by clinical evidence and Medicare guidelines. 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. Their clinic visits socialized them to the idea that transplant was the normal, logical, and right thing to do. Saying “no” to transplant would not be rational or ethical in a system in which it is expected that older persons need more medical intervention, and in which treatment can, most likely, stave off death.

The Problem of Proving “Effectiveness”

But to complicate things, in the clinic, where doctors, patients, and families seek to prolong one individual’s precious life, actual outcomes for any given person cannot be predicted. What is “effective” in studies cannot always be known in advance for any one patient, especially when that patient is quite old. Many have commented on the fact that clinical trials mostly exclude the very old and under represent those over 70. Yet it is clinical trial results that pave the way for Medicare coverage, and then, for what becomes standard and appropriate practice (Redberg 2007). In addition to all this, what is efficacious is always a

moving target, depending on new biomedical discoveries and clinical studies. So while age per se may be no indicator of successful outcome, consideration of the contexts in which age matters complicates discussions of appropriate therapy and the goals of medicine in an aging society.

Family Responsibility and Living Donation

Treatments now covered by Medicare are more complex and demanding than ever before, and they require extraordinary patient and family organization and commitment. The ethical burden of transplantation on families is enormous and largely unnoticed in the public sphere. Because living donation now exists as a potential option for many families, there is a suggestion that love can be, and perhaps should be, expressed through the offering and giving of a kidney or part of a liver. Importantly, there has been a new development in the direction of giving—from younger to older generation, reflecting the scarcity of deceased donor organs and the growing demand for organs by an aging population. This trend also illustrates two contemporary facts given to us by biomedical technology and Medicare policy: the responsibility to pursue greater health and longer life is in the hands of both the health care consumer and his or her loved ones. Responsibility, in the case of organ transplant, merges with the obligations people have for one another.

Over a 40-year period, sociologists Renee Fox and Judith Swazey (1992) Renee Fox and Judith Swazey (2002) documented the impacts of living donor organ transplantation on patients, families, medical practice, and U.S. society. They famously described “the tyranny of the gift”—that is, the imperative to offer and give, accept, and receive an organ, regardless of health or suffering, guilt, or desire—and what they called the painful “creditor-debtor vise” that may envelop givers, receivers, and families. The tyranny of the gift has additional moral and social ramifications when the direction of organ transfer is from younger to older persons. That tyranny is marked, I have found, by a sense among some recipients that this direction of transfer is “unnatural,” and by a sense among some health professionals that this direction of transfer is inappropriate from the standpoint of medical goals and use of resources.

Many older kidney and liver recipients feel obligated to live for their families, and donors feel duty-bound to allow their parent, or older relative or friend, to continue living, and to facilitate that continued life. The following form of reasoning stood out in my study of 60 kidney recipients between the ages of 70 and 81 (Kaufman, Russ, and Shim 2006): *My family needs and wants me to live because it is possible for me to do so, and I want to live. Therefore, because I need to live, they (or some of them) will offer to donate a kidney for me, and, although it may not seem right, I must accept it.*

The comment from a man, age 76, who received a kidney from his daughter is illustrative:

The children talked me into it. I said, “I’m not taking my daughter’s kidney!” But other family members persuaded me. You know, I kind of went along with my older daughter’s insistence, and we didn’t say too much one way or another, whether I wanted to or not. But I was hopeful that I could get a cadaver—right up to the night I was hospitalized. My point was, I didn’t want to take an organ from my child. If it were the other way around, I would have gladly given my kidney to one of them, but because it was coming as a hand-me-up sort of thing, I thought about it a lot. It didn’t feel like it was the right thing to do. Help should go the other way, from parent to child. I ... really ... there were times I just didn’t want to do it. There was no real point where I “decided” I wanted to have it done. I just went along with the flow. I was going along for the ride because things were being arranged for me.

His experience is not uncommon. Refusal often gives way to acceptance as health deteriorates or as donors persist in offering, because the stakes of life and relative health, the encouragement and guidance of the health-care team and family, and the routine success of kidney (and now liver) transplantation together act as imperatives to go ahead with living donation, regardless of the initial moral stance of the recipient.

When I met 74-year-old Adam Carter early in 2009, he was very ill from his decades-long hepatitis C infection and the worsening cirrhosis and progressing liver cancer that resulted. By 2008 he was extremely debilitated and exhausted. His wife recounted:

The people in the clinic 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. He just didn't want to ask them. I had a lot of qualms about it, but I wrote to Adam's sister, and it's the only time she never replied. And then our daughter said 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 horrible arguments. Because Adam was getting sicker and would say, "I want a liver." And I said, "I don't want both of you having that surgery, that risk"—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 received a deceased donor liver a month after our conversation.]

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 ordinary. 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 and want organs to survive. 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?

The placement, or indeed, offloading, of responsibility for extending life onto families is now an ethical fact in the United States, though it is rarely named as such. The full extent of the responsibilities of families in the life extension of older persons is thus largely erased from the cultural conversation about health-care delivery reform.

Cardiac Devices

The growing normalization of cardiac treatments for the oldest citizens is made possible by the decreasing risks of the procedures themselves. As devices such as automatic implantable defibrillators become smaller, as techniques for implanting them become safer, and as less invasive procedures are being used with greater frequency, physicians and the public have learned to view them as standard interventions that one does not easily refuse. Reduced risks produce a sense that life extension is open-ended *as long as one treats risk*. That is the prevailing and ordinary logic that drives so much treatment (Shim, Russ, and Kaufman 2008).

Hundreds of thousands of older Medicare recipients qualify for the implantable cardiac defibrillator, a device which, in regulating a potentially lethal heart rhythm, prevents sudden death from a heart attack, the kind of death many claim to want in late life. Use of the device has risen substantially for at least two reasons. First, in 2005 the CMS approved the expansion of the eligibility criteria to include primary prevention for patients who have never suffered a cardiac event (Redberg 2007; Tung and Swerdlow 2009). Second, a 2009 study showed the device was effective in reducing mortality for certain groups of patients over age 75 specifically (Chan et al. 2009). In 2005, after CMS approval of expanded

eligibility criteria, more than 100,000 individuals received an ICD, up from 34,000 implantations in 2000 (Hlatky 2004). In 2008, about 200,000 Americans received the device (Fleck 2009).

The “Extravaganza of Cardiology”

Although some physicians ponder the ethics and practical appropriateness of implanting this device in patients in their late 80s and 90s, several cardiologists echoed the statement of one in my study who reported: “I don’t even blink when I have a patient that comes in who is in the late 80s. I’d say the number I think twice about is 90 or above. But we have many patients over the age of 90 now.” And from another:

Now we’ve come all the way to the point where we realize, scientifically, that you can put an ICD in someone who’s never had an event at all, without doing any other testing, but just bring them in from the office and put it in. Because at some point, they may face this arrhythmia risk, and, scientifically, they’ll be better if they have this than someone who doesn’t have it. We’ve all grown to accept that.

As growing numbers of older persons receive more kinds of interventions, the “extravaganza of cardiology,” as several physicians note, becomes an increasingly ordinary part of old age. This phenomena, neither “good” nor “bad” in some simple, normative sense, is one manifestation of the diffuse ethical field at work. The source of the “extravaganza” is the confluence of clinical trial evidence, expanding Medicare coverage, and the reduced risk of device implantation, which together shape need and responsibility in the realm of cardiac care.

For practitioners and patients alike, the trend towards more sophisticated interventions at older ages influences deliberations about whether to treat. The use of one cardiac treatment along a continuum makes additional procedures with the newest devices conceivable and appropriate (Shim, Russ, and Kaufman 2008). Older patients and their families then must ponder an individual ethic of life extension, as did Mrs. Dang’s and Mr. Carter’s families. For patients, it often goes like this: *Given my current age, and given what the clinic offers, how much longer do I want to try to live?* I illustrate one common way in which this question is played out with the story of Mr. Albert, 81, a story that takes place every day in clinics across the United States.

The Case of Mr. Albert: Insuring Risk Reduction, Treating Aging

The cardiologist at a major medical clinic greeted Mr. and Mrs. Albert in 2009 and said, “I want to talk to you about a defibrillator and a pacemaker. The question is whether you might benefit from an ICD with or without pacing of the heart all the time. The defibrillator is a special pacemaker that has the ability to shock the heart in a rhythm that would lead to death. It can be thought of as an insurance policy to prevent that kind of arrhythmia. Do we want to insure the cost—for something we may not need? It’s a balance that needs to be thought of in that way, because it’s hard to predict which individuals will actually benefit from the device.

“Really,” he continued, “that’s all the defibrillator is. It’s not going to make you feel better. In fact, sometimes, it gives inappropriate shocks when it doesn’t need to. It’s extremely painful. Also, there’s risk of infection. So, it’s that type of decision.”

The doctor then offered an additional procedure because there is newer technology. The newer, resynchronizer pacer (CRT) could improve the symptoms of Mr. Albert’s advancing heart failure. The doctor continued, “If we decide to do the ICD, should we do a more extensive procedure at the same time? Putting in an extra lead in the heart, to better

synchronize the two chambers. It is a more complex procedure. We have to inject dye in the heart, go into a small vein. The cardiac resynchronizer is designed to make you feel better. The problem is, we don't know who will feel better. About two-thirds of patients will feel better; but one-third won't. So, you could undergo the surgery, and not feel better." Though he clearly invoked the "technology parade," he did not paint an unduly rosy picture.

The patient and his wife asked questions I have heard often: Is it worth it when you're in your 80s? What would you do? And of course it was impossible for the doctor to answer definitively. After more discussion, the doctor summarized the rather complex decision tree the patient now faced. He said, "There are two possibilities. First, the defibrillator—you do *qualify* for it. You are *eligible*." I have heard this exact language repeatedly, and it is important. The physician is referring to the fact that the patient's medical condition fits both the clinical trial evidence for a good outcome and the Medicare reimbursement criteria developed from the clinical trials data. To the patient, however, this language sounds as though he has won something in a publisher's sweepstakes.

"Second," the doctor noted, "we could go for the ICD and the resynchronizer, in hopes of making you feel better in terms of symptoms. But this is an unknown. And if we do that, then we have to have a plan—to stop if it's too complex, if the vein is blocked."

He concluded, "Considering your risk, it would be appropriate to buy the insurance. It's not black and white. I'm not the one who is paying the premium, having to live with infections, shocks, etc. I do think it might benefit you, that's why we are offering it." Mr. Albert's reply was a common one, based on the clinical expectation that the symptoms of heart failure in later life can be reduced, and on the societal expectation that the signs of aging can be pushed farther away (or even made to disappear) by medical technique. He replied, "I'm wearing out. Things are degenerating, deteriorating. That's why I'm here. I think I should have it." The doctor scheduled the procedure.

Together, the availability of more clinical options at ever older ages and the normalization of life-extending treatments promote the notions that aging and death are not inevitable, and that we can "grow older without aging" (Katz and Marshall 2003, p. 5). (That assumption, along with the assumption of limitless intervention, is not as pervasive in the European countries, where the limitations to health-care resources are widely acknowledged.)

The LVAD: Extreme Device to Thwart Death

The small devices have been joined, most recently, by the Left Ventricular Assist Device (LVAD), a much more formidable apparatus designed to extend the lives of people in end-stage heart failure. Patients who become eligible for the LVAD already have pacemakers and ICDs. The LVAD takes over the pumping function of the heart, and it was designed to keep people alive while they waited for a heart transplant. The first device of this kind became available through clinical trials beginning in 2000. It weighed about three or four pounds and was designed to last a maximum of two years. A new, lighter, more improved version came into use in 2005. It weighs less than one pound and is designed to last perhaps eight to 10 years. It is available as a standard therapy for those who are waiting for a heart transplant. For those not medically eligible for a heart transplant, the device is available as a permanent therapy (though, at present, only through participation in a multicenter clinical trial, being carried out at 112 centers in the United States). The expansion of the LVAD's use illustrates Latour and Venn's point about changing ends.

Though the newer version of the LVAD is quite light, the control panel weighs four or five pounds. Together with the two battery packs, which must be carried at all times, it weighs about nine pounds, a lot of weight for an individual to carry around, if one does not want to

be tethered to a 50-foot cord plugged into the wall. I have spoken with half a dozen people (all men), age 70 and above, who have this device. They use the battery packs during the day, and plug the control panel into the wall at night. This device will, no doubt, get smaller, lighter, and probably more effective for more patients in time. Evidence of greater effectiveness will be the ethical incentive for greater use, regardless of cost, especially if it enables the prolongation of what is considered by someone (patient, family, or physician) to be meaningful life. Importantly, the on-the-ground effects of this extreme treatment are highly variable.

I met a 71-year-old, fit and energetic gentleman who walked into the room where our interview was scheduled and announced to me: “I love my device.” He had received it only two months previously. He carried all the equipment in the pockets of a fishing jacket. He slung the second set of batteries, along with the recharger, over his shoulder in a tote bag. Together they weighed more than 10 pounds. He was not going to let this device slow him down. He cooked, drove, traveled. And he planned to go fishing in a boat, which his doctor advised against, because if he fell in the water he could drown.

At the other end of the continuum, I met a man, age 75, who had been hospitalized since he received the device six months before I met him. His kidneys had failed during the placement of the device, and he was on dialysis and out of conscious awareness in his hospital bed. He had recurring infections that were being treated. No one expected him to live to leave the hospital. (He died in a long-term care facility two months after I met him.) Between those two poles, I met Mr. Jones, age 80, who had been living with the LVAD for a year and a half. He was burdened by his disease and the device. He and his wife worried a great deal—could he get to a hospital if something went wrong? He had already been hospitalized a couple of times. But he also traveled and enjoyed life.

Individuals living with the LVAD are medico-cultural pioneers, experimental subjects for one of the newest cardiac technologies. When I asked those I spoke with how they came to get the device, they all told me that their doctors had said: “You will probably die in the next few months from your heart disease, and this device could give you up to five years.” The logical response—the only possible response—as one 71-year-old man reported four weeks after receiving the device, was to say, “I’ll take five years, no doubt about it.” Innovative technologies that prolong some lives will continue to emerge, to be approved for use, and, thus, to be ethically necessary. And, as both the means and the ends evolve, societal ambivalence—about value, cost effectiveness, the idea of a “natural” life span, and how much intervention is appropriate at ever-older ages—will remain.

Conclusion: Age, Expectation, and the Contours of Longevity-Making

Medicine has always pushed the boundaries of what’s possible. What’s different today is greater age, evolving expectations, and the new kinds of clinical and emotional burdens that the technological imperative and its ethical necessity foster. For clinicians, those burdens include weighing the clinical evidence against the technology parade. Clinicians are aware that some treatments, especially for the very old, can be a double-edged endeavor, yet they want, and are obligated, to provide life-extending options because the evidence shows them to reduce mortality. Older persons, many of whom are ambivalent about undergoing those treatments, mostly do not want to authorize their own deaths by proactively rejecting a potentially life-prolonging therapy, and they have hope. For families, the burden is living with the questions that are becoming so common—should I encourage her to have this treatment? What does it mean if I don’t? Am I a good enough spouse or child if I don’t offer part of an organ or push for aggressive intervention? Families do not want the responsibility of saying “no” to life-extending therapies for their loved ones, and of course they hope that

treatments can extend meaningful life. Thus, the science, the policy, the culture of medicine, doctors, patients, and families all shape the contours of longevity-making today.

The tension between our desire to make the old body ever-more malleable and to extend life because we can, on the one hand, and the desire for a death without technological interference, on the other, will not disappear. In fact, that tension will become more pronounced, in part because of the open-ended promises of science to increase longevity, and in part because the recent emphasis in academic medical centers on translational research connects the promises of the laboratory with clinical practice more directly than ever before. That connection focuses attention on the technological imperative, which becomes an ethical obligation. The ancient ethical question “How to live?” now includes reliance on and desire for medical intervention. This fact is new, and it intersects with an aging population to create new dilemmas about treatment. Today, the old question is joined by an additional one: “When does age matter, and how?” This new question is at once clinical, social, and ethical. It will continue to haunt U.S. society and medical practice for some time as policymakers, clinicians, and health-care consumers consider how to shape longevity in the years ahead.

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