

Making longevity in an aging society:

Linking technology, policy and ethics

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An explosion in the varieties of life-extending medical interventions for older persons is changing medical knowledge and societal expectations about longevity and the time for death. Longevity making today is framed by a new ethical rationality, constituted by and enabled through the routines and institutions that comprise ordinary clinical care. To be distinguished from bioethics, with its emphasis on clinical decision-making in individual situations, this new rationality is 'located' in and shaped by the value given to clinical evidence and the 'technological imperative' which, in turn, organize health care coverage policies and the shaping of standards. The new ethical rationality organizes what patients and families come to need and want. Three developments illustrate this new form of ethics 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 U.S. Medicare policy in creating need and ethical necessity. Medicare's expanding criteria for payment coverage of liver transplantation and implantable cardiac devices are the examples illustrating the pervasive logic of this new form of ethics.

[ethics, U.S. health care, technologies of life extension, aging society, health policy]

The U.S. and European populations are aging, and trends in health care delivery to older individuals are both a source and consequence of that demographic development. In the context of the growing use of potentially life-extending interventions, even for the very old and those near death, two questions emerge: How do we know and 'live' old age today? What does it mean to be old in a time of high-tech medical interventions? This essay illustrates the socio-medical-ethical pressures for clinical interventions in U.S. society, in which prevention of death is a highly valued social good.

An explosion in the varieties of life-extending interventions for older persons is re-shaping medical knowledge and societal expectations about 'normal' old age, longevity and the time for death, perhaps especially in the U.S. There is no doubt that

the rapid growth of the over-85 age group and better health for many in late life are re-defining 'old.' Robert Butler, the founding director of the National Institute on Aging, part of the National Institutes of Health in the U.S., noted 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. Treatments now routine in later life, such as renal dialysis, organ transplants, cardiac implants and surgeries, and aggressive cancer therapies are changing the nature of 'end-stage' disease. In many cases, formerly terminal illnesses have become manageable diseases, and attention to chronic risk and ongoing medical surveillance have become the norm. These developments both contribute to and result from a growing cultural expectation: doctors and patients alike expect medical treatment that will manage disease at all ages (President's Council on Bioethics, U.S. 2003). Moreover, these developments are influencing family and medical responsibility in ways that could not have been predicted even a decade ago.

In the U.S. specifically, 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 to resist interventions that prolong dying and suffering, on the other. That tension is becoming more deeply entrenched in the U.S. 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 the authority of medical knowledge and medicine's progress in curing and preventing disease. It would deny the importance of the scientific context of clinical practice. And it would deny the assumption that doctors are considering what is best for *this* patient – an individual with particular diseases and symptoms.

Re-thinking what constitutes 'ethics'

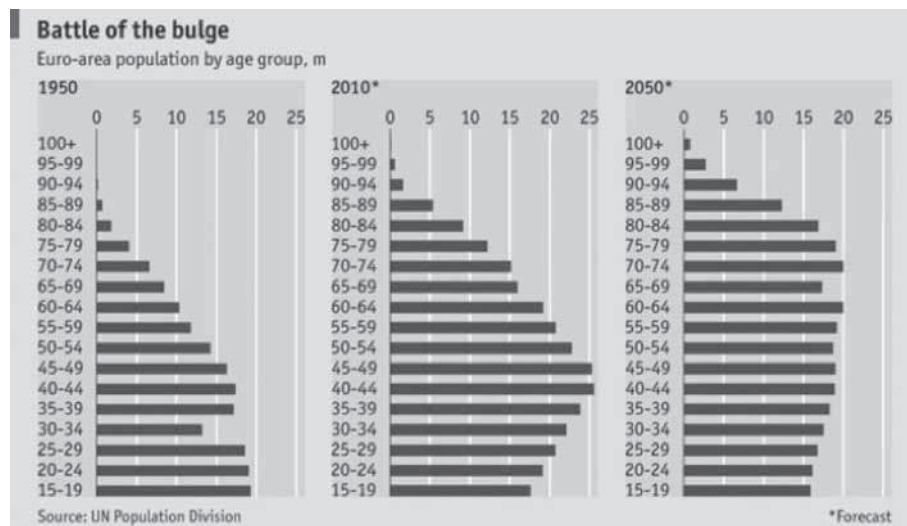
Notions of aging, expected longevity and appropriate medical care as one ages are mutable of course, grounded in historical moments, cultural innovation and social norms. The vast array of technologies and procedures now available to prolong life at older ages and the complex infrastructure of U.S. clinical care that supports them give rise to a new way of considering ethics.

This essay conceptualizes and describes 'the ethical' as part of a broad socio-structural terrain constituted in and through political-economic structures, the organization of treatment practices and their effects on health providers, patients and families. In doing so, it moves away from earlier conceptions and uses of bioethics, which assumed, in the U.S., that problems in medicine were located at the level of the doctor-patient relationship and which, therefore, stressed improved communication, analysis of conflicting values, and autonomous decision-making between the physician and the patient. The broader conceptualization of ethics explored here stands on the shoulders

of, and displaces, that older kind of ethics – including the debates, in the 1960s, about rationing kidney dialysis to ‘deserving’ citizens, and the concern, beginning in the 1970s with comatose Karen Quinlan, about who has the authority to 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 while the normative concerns central to bioethics remain, a more complex pattern of health care organization and fragmentation has emerged in the U.S, 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.

Conceptualizing ‘ethics’ as constituted in and through the structures of health care organization may provide a cautionary tale for directions in health care delivery in Europe, especially in the context of the expanding use of life-extending technologies at older ages (such as renal dialysis, organ transplantation and cardiac implantable devices) and in the context of debates about state responsibility for medical care and the need for cost-control.

Figure 1 Battle of the bulge



The first task of this anthropological essay is to map the socio-ethical changes taking place in the delivery of medical care to U.S. citizens. The second task is to analyze the ways in which these changes are affecting medicine and the quality of individual experience, especially the experience of growing older. The essay touches upon some difficult issues facing health care today, especially: new technologies and their open-ended use, and a few of the ways in which age does and does not matter. It also discusses what gets minimized and erased from U.S. clinical and policy discussions in the lure of life-extending treatments.

At least three developments illustrate the way in which ethics ‘resides’ beyond the doctor-patient relationship and, instead, is constituted now in and through the structures of health care organization. These are: the changing nature of disease, the role of technology, and the role of Medicare policy – the U.S. government program that pays for acute medical treatment for persons age 65 and over.

The changing nature of disease

In his book, *The Longevity Revolution* (2008), Robert 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). Rosenberg continues:

What do I mean when I describe disease as a ‘social entity’? I refer to a web of practice guidelines, disease protocols, laboratory and imaging results, meta-analyses, and consensus conferences. These practices and procedures have over time come to constitute a seemingly objective and inescapable framework of disease categories, a framework that increasingly specifies diagnostic criteria and dictates appropriate therapeutic choices (p. 5).

The ramifications of Rosenberg’s insight for health professional, patient and family understandings of responsibility about treatment standards and appropriate care become apparent when we conceptualize ethics as constituted by and through political and economic rationality and the organization of interventions and their effects. 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, their families 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 easily and 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 the future – perhaps especially the idea of

time left – 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.

Indeed, personal responsibility today consists largely of awareness of health risk and disease prevention strategies. 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. One response to risk awareness and disease prevention is what Kathleen Woodward (1999) calls “statistical panic”– the anxiety, perhaps especially in the U.S., 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 broadened conception of ethics is the role of technology. For clinicians, the unavoidable ‘technological imperative’ in medicine, first described by health economist Victor Fuchs (1975), becomes, also, a moral imperative. Anthropologist Barbara Koenig (1988) 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” (Koenig 1988). “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 mostly, by the value given to clinical trial results). Once new technologies are approved, they often are extended far beyond the populations on which they were originally tested. An assumption of benefit, which may or may not be true, drives that extension. Technical ability (via drugs, devices and procedures) becomes ethical necessity.

In an aging society, the role of technology is complicated because studies show that renal dialysis, major surgeries, cardiac defibrillators, chemotherapy, and other treatments for persons in later life with multiple chronic conditions sometime open

up a murky ethical terrain in which the press to prolong life comes up against the cry to reduce suffering. 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. The value placed on risk awareness has also led to the many debates in the U.S. today about screening technologies for older persons (especially regarding prostate, breast, and colon cancer screening), debates that have spilled over from medical journals to the front pages of newspapers.

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. This connection between value of life remaining and technical ability has become one of the problematic features of U.S. medical care because of the rapidly rising costs of technology use in an aging population. For everyone, as the risks associated with different technologies diminish – and cardiac surgeries and organ transplantation are good examples of that – the social and medical perception of risk shifts to the risks of death, and doing everything possible to reduce those risks, even, in the U.S., regardless of age and disease state.

In exploring the relationship between technology and morality, Latour and Venn (2002) point out the ways in which technologies of all kinds are not merely means to specific ends, and they show that 'ends' are not static and already known. Rather, they describe 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.

The mechanical ventilator provides an example of the way in which the use of a technique modifies the original intention. It was developed over a 50-year period in response to the demands of surgeons who needed to maintain patients' respiratory function while they operated on hearts, lungs and other organs. The mechanical ventilator became standard equipment in American hospitals by the mid-1970s. Within a few years, the mechanical ventilator was indicated for a long list of diseases and problems. Recovery from life-threatening pneumonia or chronic obstructive lung disease became possible. Because that technology keeps the organs of the dead oxygenated, it opened up the realm of organ transplant beyond anything previously imaginable. But, as is well known, the technology quickly came to be used (in the U.S.), also, to keep people 'alive' who are in a vegetative state, leading to a new world of dilemmas about

familial, medical and legal responsibility, and new questions about personhood, life and death (Kaufman 2000).

Role of Medicare policy in establishing ‘need’

The third development illustrating this new form of ethics is the role of Medicare policy in setting the stage for what counts as appropriate practice and ethical necessity. Medicare, which influences coverage decisions among private insurers, is essential background to what becomes standard of care medical practice in the U.S. Committees that administer the Medicare program continually review 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 treatment for life-threatening 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 trial 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 of the overall risks and benefits of a drug, device, procedure or service are the most important factor in determining reimbursement. Importantly, series of clinical trials that show benefit for the use of a specific intervention on younger adults increase the pressure on Medicare to expand payment coverage for ever-older adults – even without evidence of effectiveness for older persons. It is useful to think of Medicare as a tool through which the U.S. government and American taxpayers, together, shape longevity-making. It is central to the ethics of managing life. By enfolded the logic of evidence-based therapeutics into its coverage policies, and by providing coverage for older adults even when evidence is lacking, Medicare creates both the infrastructure and the value for the linkages among need, ethics, and longevity-making to occur. This feature of Medicare ethics has been absent from debate about cost control in U.S. health care delivery.

Two recent examples of therapies that have shifted from ‘unthinkable’ even a decade ago to routine and standard treatment for older persons in the U.S. 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 health professionals, but it is established, first, by what becomes standard, reimbursable treatment. One cannot *need* a therapy that has not been proven effective. *Need*, of course, affects patients’ and families’ lives. Examples from Kaufman’s ethnographic research in the U.S. illustrate the emergence of need, first in the case of liver and kidney transplant, 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 (as it has for other treatments) so that, for persons age 65 and beyond, previously fatal liver diseases are now objects of treatment. Medicare began payments to hospitals for liver transplants among Medicare beneficiaries in 1991, but only for a limited number of diagnoses. By 2001 studies showed that outcomes for patients with cancer that originates in the liver (hepatocellular carcinoma) improved with transplantation. Medicare coverage for eligible patients began that year. Transplantation for liver cancer has grown steadily ever since and there is no doubt that it saves lives. Liver transplants are performed in 127 American centers and they are the second most common organ transplant operation (after kidneys) in the U.S. Though the numbers are not large, the percentage of liver transplants for older persons is rising. More than 6,300 (6320) liver transplants were performed in 2009, 11% of them on adults over 65 years of age (Organ Procurement and Transplantation Network 2011). Older patients Kaufman met in different centers in the U.S. 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 transplantation becomes ethically necessary to avoid death. The individual ethical decision making that takes place downstream – and which has been the focus of clinical bioethics – is already pre-figured by the confluence of clinical evidence, Medicare coverage, standard technology use and, therefore, the creation of need.

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 payment 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 is now scientifically adequate to show safety and positive outcomes. Payment decisions are, in fact, ethical priorities because access, health and survival are at stake.

The story of Mrs. Dang: The logic of transplantation

Mrs. Dang’s story is illustrative. Her daughters brought her, at age 72, to the liver clinic at a major medical center liver clinic because her chronic liver disease was becoming more advanced, and her local doctor suspected cancer. In three clinic visits, over an eight month period, the patient and family moved from ambivalence about such a major intervention to acceptance of it – in order for Mrs. Dang to live.

At the first clinic visit, the daughters asked, Will a transplant extend her lifespan? or shorten it? Will it make her life worse? How would it complicate their own lives,

if she didn't do well? if one of them were a donor and had complications? 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, getting the transplant, and then she could live nine to fifteen years with no problems." Mrs. Dang did not want a transplant.

Walking out of the clinic building, one of Mrs. Dang's daughters said, "I need to ask my mother if she wants to live ten more years." This kind of statement has become ordinary. This kind of thinking reflects a new relationship among value, time, technology and life course expectation. It 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, ten, or fifteen 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 potentially 'added time' would naturally result from treatment.

At the second clinic visit six months later, the liver specialist presented the family with the numerical evidence: ten percent of patients die in the first year; ninety percent survive at least three years. And he said, "I think she would benefit from a liver transplant." The family walked out of the clinic extremely ambivalent.

Two months later, Mrs. Dang had turned 73. In the waiting room, the daughters explained that the idea of a transplant was a huge dilemma for them. They worried that, at age 73, their mother would suffer complications and become more frail, 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, in the U.S., to families as they respond to the prospect of this and other life-extending interventions, as they respond to the technological imperative, the risk of death and the value placed on clinical evidence. Families do not often discuss those worries in the clinic because the lure of the evidence for life extension is so powerful. The ethical responsibilities that rest on their shoulders thus often remain invisible to clinicians.

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?" Those reflections – in which families feel a huge burden of guilt and complicity, as though they could be 'killing' or 'saving' a loved one – are common in the U.S. today. Those reflections are a downstream effect of technological innovation and its legitimacy, first by Medicare reimbursement, and then by what becomes standard, ethical practice at ever-older ages. 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. The odds are that she's not going to live very long without it. She has an 80% – 90% chance of making it through the first year. She

may have a little more trouble because she is older. Mrs. Dang, at that point, said, “I’ve made up my mind just now. It’s okay. I’ll do it to live.” The doctor asked the daughters if they agreed, and they said “yes.”

Thus Mrs. Dang moved toward liver transplant because standard research and clinical pathways, expanded payment criteria, and professional and familial obligation all led toward that outcome. The doctors were guided by clinical evidence and Medicare guidelines. For the family, saying ‘no’ to transplant would not be rational or ethical in a system in which treatment can, most likely, stave off death.

When we think about the uses of ever-more technology on greater numbers of older persons, age matters in relation to cost, allocation and scarcity because there are more older people than ever before and because more of them seek and demand potentially life-extending, high-tech medical treatments into very old age. Yet in tension with pressures on cost and allocation brought about by an aging population, published evidence in medicine and values in American society show that transplant and other procedures successfully prolong the lives of older persons (Chan et al. 2009; Lipshutz et al. 2007). In those studies, advanced age per se does not indicate ineffectiveness of the therapy. Geriatricians and other specialists know this well.

But to complicate things, in the clinic, where doctors, patients and families seek to prolong one individual’s precious life, actual outcomes for any one person cannot be predicted. Many have commented on the fact that clinical trials mostly exclude the very old and under-represent those between the ages of 70 and 80. Yet it is clinical trial results that pave the way for Medicare coverage, and then, (in the U.S.) for private insurance coverage and what becomes standard practice. In addition to this, what is effective in studies is, always, a moving target. So, while age per se may be no indicator of successful outcome for any one patient, the use of limited, costly medical resources on an expending elderly population complicates discussions of appropriate therapy and the goals of medicine in an aging society.

Living donation, families and responsibility

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 organ donation now is an 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 Renée Fox and Judith Swazey (Fox & Swazey 1992; Fox & 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 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 kidney 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 Kaufman’s study of 60 kidney recipients between the ages of 70 and 81 (Kaufman et al. 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 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 Kaufman met 74 year old Adam Carter in 2009, he was very ill from his decades-long Hepatitis C infection and the worsening cirrhosis and progressing liver cancer that resulted. 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 pack-

ets 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 United Network for Organ Sharing (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 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 making longevity reside?

The enormous care-giving and emotional burdens on families, their work involved in making longevity, are not considered part of the bioscientific evidence base that determines so much about life prolonging treatments today. The placement, or indeed, off-loading of responsibility onto families becomes part of a diffuse ethical normalcy in which we all live, though it is rarely named as such. The full extent of the responsibilities of families in an aging society is thus largely erased from the cultural conversation about health care delivery in the U.S.

Cardiac devices

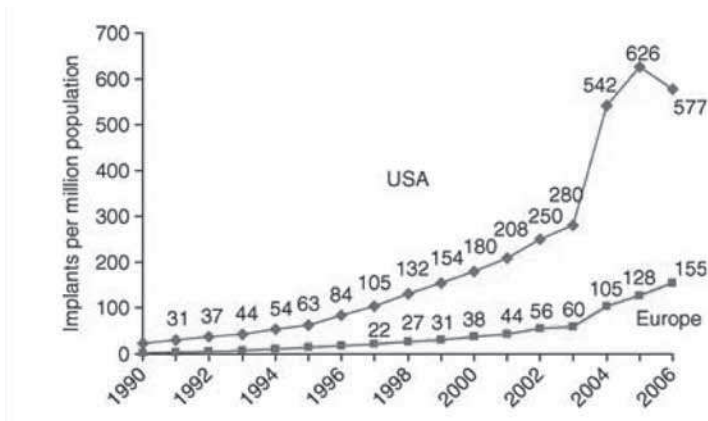
The growing normalization of cardiac treatments for the oldest citizens is made possible by the decreasing risks of the procedures themselves. As devices such as automatic implantable cardioverter defibrillators (AICDs or ICDs) become smaller, as techniques for implanting them become safer, and as less invasive procedures are being used with greater frequency and success, physicians and the public have learned to view them as standard interventions that one does not easily refuse. In the U.S. 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 et al. 2008).

Hundreds of thousands of Medicare recipients fit clinical trial criteria for the implantable cardioverter defibrillator. The device was used sparingly up to 2002-03 for those who had already survived a potentially lethal rhythm but were at high risk for another life-threatening cardiac event. In the past few years, use of the device has risen substantially for two reasons. First, following a series of clinical trials, Medicare committees in 2005 expanded the eligibility criteria to include primary prevention for those who have never suffered a potentially fatal rhythm disturbance (Redberg 2007; Tung & Swerdlow 2009) – thus illustrating Latour and Venn's point about changing

ends. Secondly, the ICD is used routinely now along with the cardiac resynchronizer, the CRT, in more sophisticated multi-function devices. In 2008, more than 340,000 American received an ICD, up from 34,000 in 2000 (Grant 2010). Currently, one-fifth of ICD and CRT devices are implanted in persons over 80 (Swindle et al. 2010). Kaufman learned from several medical centers in 2008-9 that approximately 10% of these devices go to persons over age 90. The important thing about the ICD is that, in treating a potentially lethal arrhythmia, it prevents sudden death, the kind of death many say they actually want in late life.

A review of European utilization of the cardiac devices in 2010 shows that the U.S. implantation rate is four times the European rate for the ICD and for the CRT though the European rate is increasing and there is great variation among European countries (Camm & Nisam 2010).

Figure 2 ICD/CRT-D implantations per million of population in Europe and USA by year

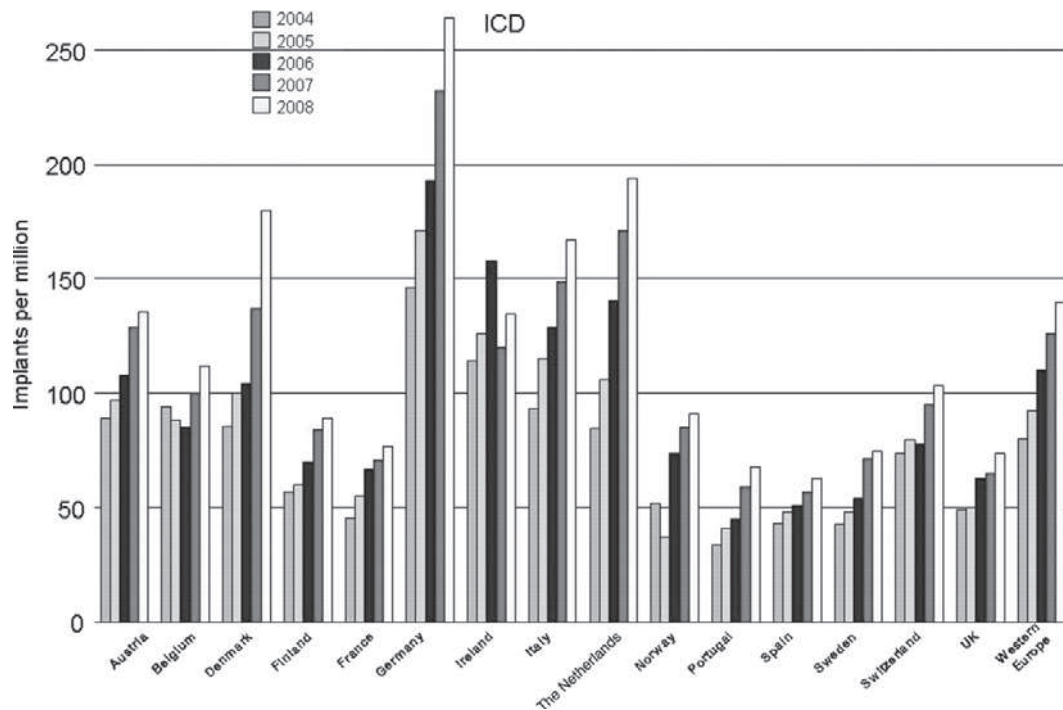


The authors of that review attribute lower European usage to the fact that, on a per capita basis, Europe has a far smaller number of implanting centers and electrophysiologists than does the U.S. (Camm & Nisam 2010). Thus, there are fewer referrals to those specialists and those centers, even when patients meet the internationally accepted clinical trial criteria. Yet, European usage of the device and the rates of increasing usage are uneven across the European countries (Van Veldhuisen et al. 2009).

Although some U.S. physicians ponder the ethics and practical appropriateness of implanting this device in patients in their late 80s and 90s, several electrophysiologists echoed the statement of one who reported, “I don’t even blink when I have a patient that comes in who is in the late 80s, because that has become the standard. 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 to realize 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. So I think I've changed in terms of my thinking about what's treatable or when it should be treated."

Figure 3 Changes in ICD use in Europe, 2004-2008



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 is one manifestation of the fact that ethics is broadly entrenched in and constituted through the organization of health care. 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, et al. 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, that is, how long I have already lived, how much longer do I want to try to live, given the options of medicine?* The story of Mr. Albert illustrates this treatment trend and common patient response. It is a story that takes place every day in clinics across the U.S.

The story 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 have spoken with your local doctor. 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. It’s important to think about the defibrillator as an insurance policy. Do we want to insure the cost – for something we may not need? 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. Over a 5 year period 5-10% of patients will experience that kind of shock. It’s extremely painful. Like a kick in the chest. Also, there’s risk of infection. And you’ve heard about the recalls, the faulty devices. 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, to treat the heart failure. It is a more complex procedure. We have to inject dye in the heart, go into a small vein. This pacer, 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 what some American clinicians refer to as the ‘technology parade,’ he did not paint an unduly rosy picture.

Mr. Albert and his wife asked common questions: 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*.” Kaufman 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 lottery.

“Second,” the doctor noted, “we could go for the ICD and the re-synchronizer, 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. It’s up to you. 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 and approaching death can be pushed farther away 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.” He gave his consent, and the doctor scheduled the procedure.

The Left Ventricular Assist Device (LVAD): Extreme device to thwart death

Those small devices have been joined, most recently, by the Left Ventricular Assist Device, 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 lighter, more improved version came into use in 2005. It weighs less than one pound and is designed to last perhaps eight to ten years. It became available, first, as a therapy for those waiting for a heart transplant. But its use has expanded as well, illustrating the point of Latour and Venn about changing ends. For those not medically eligible for a heart transplant, the device now is available as a permanent therapy. About 10,000 Americans have had one of these devices implanted. Already, it has come to seem ordinary in the U.S. (Cooper et al. 2011; Grady 2010). 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 to be meaningful life. It is a good example of how the technological imperative so quickly becomes an ethical necessity.

Importantly, the on-the-ground effects of this extreme treatment are highly variable. Kaufman met a 71 year old gentleman in 2009, fit and energetic, who walked into the room where our interview was scheduled, and announced: “I love my device.” He had received it only two months previously. He carried all the equipment in the pockets of a fishing jacket. The second set of batteries, and recharger, he slung over his shoulder in a tote bag. 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, a 75 year old man was hospitalized for eight months after he received the device. His kidneys had failed during the placement of the device and he was on dialysis and out of conscious awareness in his hospital bed. No one expected him to live to leave the hospital. (He died in a long-term care facility two months after Kaufman met him.)

Individuals living with the LVAD are medico-cultural pioneers, experimental subjects for one of the newest cardiac technologies. So are their families, on whom the

burdens of care settle. When asked how they came to get the device, patients replied 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 to be, thus, ethically necessary. And, as both the means and the ends evolve, societal ambivalence – about value, cost effectiveness, the idea of ‘natural’ life span, and control over the timing of death – will remain.

Conclusion: Ethical rationality and longevity making

Medicine has always pushed the boundaries of what is possible. What is different today is greater age, changing 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.’ For patients, those burdens include feeling the need to pursue treatments to stay alive, sometimes for their families. 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? Clinicians need to be aware that these questions are now inescapable, though not often articulated.

This new ethical rationality and normalcy is diffuse and therefore, difficult to discern. It is located in health care policies, in standard and emerging technologies, and in the clinical evidence that supports technology use. It is located as well in what patients and families come to need and therefore, to want. Importantly and ultimately, it is located in the physical care-giving tasks and the emotional burdens placed on families. It is important to consider ethics as constituted in and through the structures and activities that organize and shape contemporary health care delivery. In this way we see that everyone is enveloped in its logic and routines – clinicians, patients and families alike. Though relatively new, it has already become like the air we breathe, mostly unnoticed.

This anthropological essay has traced the sources and effects of this transformation, which is fostered through a variety of means. Evidence-based medicine, policy decisions, the technological imperative and the ways in which technologies shift the ends of medicine guide everyone toward the newest treatments, which are constantly emerging. Clinicians are aware that some treatments, especially for the very old, can be a double-edged endeavor, yet they want – and we want them – to provide life-extending options. Older persons, many of whom are ambivalent about undergoing aggressive treatments, mostly do not want to authorize their own deaths by rejecting a potentially life-prolonging therapy. Finally, 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 and their responsibilities, 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 bioscience 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, at least in the U.S., reliance on and desire for medical intervention at every life stage. This recent fact intersects with an aging population to create dilemmas about treatment that U.S. society faces now and, that perhaps, European countries will face in the future. Today, that 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 aging societies and medical practice for some time as policymakers, clinicians, patients and families consider how to shape longevity in the years ahead. Both those questions are very much at stake today in considering, and acting on, the fate of old age.

Note

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References

- Beck, U.
1992 *Risk society: Towards a new modernity*. London, Newbury Park, Calif.: Sage Publications.
- Butler, R.N.
2008 *The longevity revolution: The benefits and challenges of living a long life*. New York: PublicAffairs.
- Camm, A.J. & S. Nisam
2010 European utilization of the implantable defibrillator: Has 10 years changed the 'enigma'? *Europace* 12: 1063-69.
- Chan, P.S. et al.
2009 Impact of age and medical comorbidity on the effectiveness of implantable cardioverter-defibrillators for primary prevention. *Circ Cardiovasc Qual Outcomes* 2 (1): 16-24.
- Cooper, H., L.K. Altman & M.D. Shear
2011 After heart procedure, Cheney re-emerges with new outlook. *New York Times*, January 5.
- Crawford, R.
2006 Health as a meaningful social practice. *Health* (London) 10 (4): 401-20.
- Fox, R.C. & J.P. Swazey
1992 *Spare parts: Organ replacement in American society*. New York: Oxford University Press.
2002 *The courage to fail: A social view of organ transplants and dialysis*. New Brunswick, NJ: Transaction Publishers.
- Fuchs, V.R.
1975 *Who shall live? Health, economics, and social choice*. New York: Basic Books.
- Giddens, A.
1991 *Modernity and self-identity: Self and society in the late modern age*. Stanford, Calif.: Stanford University Press.
- Gillick, M.R.
2007 The technological imperative and the battle for the hearts of America. *Perspect Biol Med* 50 (2): 276-94.
- Grady, D.
2010 When your heart pump ticks down. *New York Times*, August 10.
- Grant, M.
2010 Ethical and attitudinal considerations for critical care nurses regarding deactivation of implantable cardioverter-defibrillators. *AACN Adv Crit Care* 21 (2): 222-26.
- Jonsen, A.R.
1998 *The birth of bioethics*. New York: Oxford University Press.
- Kaufman, S.R.
2000 In the shadow of "death with dignity": Medicine and cultural quandaries of the vegetative state. *American Anthropologist* 102 (1): 69-83.
- Kaufman, S.R., A.J. Russ & J.K. Shim
2006 Aged bodies and kinship matters: The ethical field of kidney transplant. *American Ethnologist* 33 (1): 81-99.

- Koenig, B.
 1988 The technological imperatives in medical practice. In: M.M. Lock & D. Gordon (eds), *Biomedicine examined*. Boston: Kluwer Academic Publishers, pp. 465-96.
- Latour, B. & C. Venn
 2002 Morality and technology: The end of the means. *Theory, Culture & Society* 19 (5/6): 247-60.
- Lipshutz, G.S. et al.
 2007 Outcome of liver transplantation in septuagenarians: A single-center experience. *Arch Surg* 142 (8): 775-81; discussion 781-84.
- Organ Procurement and Transplantation Network
 2011 The Organ Procurement and Transplantation Network Data.
- President's Council on Bioethics (U.S.)
 2003 Beyond therapy: biotechnology and the pursuit of happiness. New York.
- Redberg, R.F.
 2007 Disparities in use of implantable cardioverter-defibrillators: moving beyond process measures to outcomes data. *Jama* 298 (13): 1564-66.
- Rose, N.
 2007 *The politics of life itself: Biomedicine, power, and subjectivity in the twenty-first century*. Princeton, NJ: Princeton University Press.
- Rosenberg, C.E.
 2007 *Our present complaint: American medicine, then and now*. Baltimore: Johns Hopkins University Press.
- Shim, J.K., A.J. Russ & S.R. Kaufman
 2008 Late-life cardiac interventions and the treatment imperative. *PLoS Med* 5 (3): e7.
- Swindle, J.P. et al.
 2010 Implantable cardiac device procedures in older patients: Use and in-hospital outcomes. *Arch Intern Med* 170 (7): 631-37.
- Tung, R. & C.D. Swerdlow
 2009 Refining patient selection for primary prevention implantable cardioverter-defibrillator therapy: reeling in a net cast too widely. *Circulation* 120 (10): 825-27.
- Tunis, S.R.
 2004 Why Medicare has not established criteria for coverage decisions. *New England Journal of Medicine* 350 (21): 2196-98.
- Van Veldhuisen, D.J. et al.
 2009 Implementation of device therapy (cardiac resynchronization therapy and implantable cardioverter defibrillator) for patients with heart failure in Europe: Changes from 2004 to 2008. *Eur J Heart Fail* 11 (12): 1143-51.
- Woodward, K.
 1999 Statistical panic. *Differences: A Journal of Feminist Cultural Studies* 11 (2): 177-203.