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Making Longevity in an Aging Society: Linking Ethical Sensibility and Medicare Spending

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Abstract

An aging U.S. society, a growing array of life-extending medical interventions, Medicare policy and an ethic of individual decision-making together contribute to the deepening societal tension between controlling health care costs and enabling health consumer use of life-sustaining technologies. The activities that constitute longevity making, like so many other socio-medical practices, constitute a site for the governing of life and the emergence of new forms of ethical comportment and social participation. Those activities – including the necessity of treating risk, the difficulty of saying 'no' to evidence-based interventions and the responsibility of choosing among clinical options -- also lie at the heart of debates about health care rationing and reform. Cardiac procedures, organ transplantation and cancer treatments are three examples of medicine's success in extending life and are emblematic of the existential and societal quandaries that result. A perspective from medical anthropology shows the ways in which the making of life is linked to health care spending and the ongoing debates about age-based rationing.

Keywords

health care reform; age rationing; privatized ethics; self-care

With health care reform and especially Medicare reform on the front pages and at the forefront of the Obama administration agenda, a perspective from medical anthropology can highlight some of the socio-cultural sources of emergent and recalcitrant obstacles to cost containment efforts and can show, too, why the topic of age rationing continues to be a significant point of ongoing tension and lack of resolution.

An explosion in the varieties of life-extending interventions for older persons is changing the face of many medical specialties in the U.S. Routine and innovative treatments are prolonging more lives at older ages than ever before, and the average age of persons who receive surgery or other non-primary care interventions that extend life is rising. Indeed, octogenarians comprise the most rapidly growing group of surgical patients and there is a growing medical literature on the justification and benefits for performing many kinds of procedures on persons over the age of 80. These practices are re-shaping medical knowledge and societal expectations about 'normal' old age, ordinary medical treatment and the time for death. For example, medicine's successes have promoted the widespread assumption that its techniques can almost always restore health; practitioners and patients alike consider the

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body malleable, treatable at any age; and death is not often expected, even for those who are very old and extremely ill. The activities that constitute longevity making, like so many other socio-medical practices, constitute a site for the governing of life and the emergence of new forms of ethical comportment and social participation. Those activities also lie at the heart of debates about health care rationing and reform.

For clinicians, there are no longer steadfast assumptions about technological or biological limits to what medicine can do for older persons. Many persons turned patients, for their part, along with their families, have become medical consumers questing after their own health and longevity. Desire for therapeutics into advanced age has grown along with the aging of the U.S. population. Risk reduction has become, more and more, a way of life for affluent sectors of society. The boundaries among prevention, enhancement, maintenance and cure become murky as patients and doctors work to treat risk. At the same time and in response to these medico-cultural phenomena, evidence-based clinical studies encourage and allow the Medicare program to expand its criteria for cost coverage of procedures, so that more technologies for risk reduction, along with more disease treatments, become Medicare approved and thus standard care (Bach 2009; Neumann, Rosen and Weinstein 2005). These developments contribute to the rising costs of health care delivery – particularly for the Medicare program – and point to the societal challenge of controlling those costs.

Existential quandaries accompany cost challenges. Responsibility for decision-making about the uses of treatments (for risk reduction, life prolongation and staving off death) has become an individual matter in the neoliberal, post-paternalistic era. Responsibility gives rise to the following question: *How much longer do I want to try to live, given what the clinic offers for my (potentially) life threatening condition?* This question, pondered privately though confronted broadly by older persons in the U.S, can be said to characterize the ethical ground of the contemporary moment, vis a vis health, the self and the clinic. That ethical ground is comprised of a sensibility about the relationship among clinical offerings, risk perception, time and the worth of *time left.* The primacy and, indeed, inescapability of this question is a testament to the way in which a deliberative, privatized ethics about the timing, control and quality of the end of life becomes embodied as a reflexive, often obligatory self-care practice. Importantly, this question links the making of life to health care spending and Medicare policy. By allowing payment for increasing numbers of therapies for more conditions, that policy enables doctors to prolong more lives, and it enables (and incites) patients and families to seek the extension of life in more circumstances and into older age, because it is their responsibility to do so.

4.5 million people in the U.S. are 85 and older. By 2050 persons over age 85 will increase to 20 million. There are enormous pressures from multiple sources -- patients themselves, their families, the ‘technological imperative’ in medicine, the structure of health care financing, the specter of litigation, the excitement surrounding new (and possible) interventions, professional training and sub-specialization, and above all, the cumulative successes of clinical medicine -- to attempt to stop the course of end-stage disease in later life. 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). (The assumption of intervention in late life is not as pervasive in many parts of Europe, where the limitations to health care resources are widely acknowledged.) Two additional trends contribute directly to rising costs and the problem of limiting them. Diminishing the risks of death by whatever clinical means are available has already become standard practice and standard ethics -- for those who can access treatments. Ever-new diagnostic tools create more perceived ‘need’ on the part of both providers and patients to intervene, in order to stop or slow disease progression and treat the risk of death.

Examples of the expanding use of three kinds of therapies in the U.S. -- cardiac procedures, organ transplantation and cancer treatments -- are emblematic for the rising age for interventions of all kinds. Their success in extending lives and enhancing well-being puts pressure on providers, patients and their families to employ them because they are clinically indicated, because we want ‘the best’ for our loved ones and because one does not easily say ‘no’ to standard of care medicine. In addition, hope resides in interventions, in *doing something*, and so it is difficult for everyone involved to say ‘no’ to therapies that may extend life when they are offered and available. This situation contributes to both existential and societal quandaries.

Hundreds of patients and families I have observed and spoken with[1] in major medical center clinics articulate a range of opinion about the desire for life prolonging interventions. Some unequivocally want more treatments in the hopes of life-prolongation, even when physicians indicate that more therapies will not stop the course of disease and that it is time for hospice. Others decline aggressive interventions once a life-threatening or terminal diagnosis had been made, though their lives might well be prolonged. Most persons, however, sit between these two poles. Many equivocate and say both ‘yes’ and ‘no’ to therapies. Some are unwilling or unable to choose treatments in what health professionals consider a ‘timely’ manner. Some remain uncertain about the worth, to themselves, of continued life within a clinical regimen. Often neither desire nor actual choice is clear-cut and, over time, patients and families do change their minds about the kinds of treatments they will accept (Fried et al., 2007;Russ, Shim and Kaufman 2005;Shim, Russ and Kaufman 2007). Health professionals, for their part, mostly want and need to weigh their understanding of the scope and value of aggressive, potentially life-extending therapies against patients’ desires.

Cardiac procedures

Coronary artery bypass graft surgery, together with angioplasty and stent procedures, are now commonplace for persons in their 80s and not unusual for persons in their 90s. Cardiac valve replacement therapies are becoming more common in the ninth decade as well. Studies in the medical literature indicate that successful outcomes for those procedures can be obtained for select groups of patients aged 90 or older, though hospitalization may be longer and morbidity may be higher than for younger patients.

Advances in treatments for strokes and heart attacks have prolonged lives, though they have led also to more heart failure among the elderly. The prevalence of heart failure has been increasing over the last decade, with approximately 550,000 new cases diagnosed each year. The median life expectancy for persons with symptomatic heart failure is less than five years. These facts are background to a recently articulated ‘problem’ in medicine – the challenge of predicting life expectancy in order for patients and physicians to ‘choose’ between life-sustaining and palliative therapies (Yancy 2008). Available interventions for severe heart failure at the present time include hospice care, the automatic implantable cardiac defibrillator (AICD), which corrects a lethal heart rhythm, the ventricular assist device (VAD), a mechanical pump that helps a weak heart pump blood through the body, and heart transplant. These dramatically distinct offerings include both ends of the intervention spectrum in contemporary medicine – from end-of-life palliation to aggressive, heroic (yet only potential) life-extension. This range of treatments complicates choice because hope is always embodied in heroic interventions. A recent study shows that patients

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[1] along with collaborators Lakshmi Fjord, Ann Russ and Janet Shim.

who think their chances of relatively long-term survival are favorable want aggressive therapies -- despite prognostic models to the contrary (Allen et al., 2008).

Relatively few individuals consider and receive a VAD or cardiac transplant, although cardiac transplant in the seventh decade is not uncommon. In contrast thousands of older Medicare recipients now qualify for the AICD device (with or without pacemakers) under expanded medical criteria developed during clinical trials. The device, by regulating a lethal cardiac rhythm, treats the risk of a fatal heart attack. Use of the device is rising substantially because the Centers for Medicare and Medicaid Services in 2005 approved the expansion of the eligibility criteria to include primary prevention for patients who have never suffered a cardiac event. In 2005 more than 100,000 individuals received an AICD, up from 48,000 in 2001.

Although a recent study shows the device to be effective in reducing mortality for older patients specifically, opinions diverge about whether the AICD for very old individuals is appropriate therapy. Advising a patient in the 8th or 9th decade to implant an AICD as a preventive strategy carries with it implications that patients and families do not necessarily foresee. Postponing death from a heart attack allows one to suffer from the symptoms of heart failure and a host of degenerative conditions. As devices become smaller and techniques for implanting them become safer, physicians and the public have learned to view them as standard interventions that are justified and that one does not, easily, refuse. Reduced risks associated with all these procedures produce a sense that life extension is open-ended as long as one treats risk (Shim, Russ and Kaufman 2006).

Kidney and liver transplant

Medical evidence shows that transplant is the treatment of choice for suitable patients with end stage renal disease, offering a better prognosis than the continuation of dialysis. This fact is both source and effect of the growing demand for kidney transplantation among older persons with kidney disease – both from patients already on dialysis and from those who would like to avoid dialysis altogether. The number of kidneys transplanted to people over 65, from both living and cadaver donors, has increased steadily in the past two decades in the U.S. In 2008 15% of all kidney transplants went to persons age 65 and over (for a total of 2518 transplants) up from 2% in 1988 and 11% in 2003. Transplants are no longer unusual in the seventh decade of life and are sometimes performed into the early 80s.

Patients over age 65 have the option of remaining on the national UNOS (United Network for Organ Sharing) waiting list up to seven years for a ‘younger’ cadaveric kidney, waiting two to four years for an ‘older’ cadaveric kidney, or taking a kidney from a living person – with virtually no waiting time. Older patients and their families quickly learn that their ‘choice’ must take into consideration time and age because the older you are, the more precarious your health may become in a few years, and thus, the greater the urgency for a transplant. As more older people become medically eligible for kidney transplants while the waiting time for cadaveric kidneys increases, the greater the ethical pressure on family members and others to become living donors. Thus it is not surprising that living kidney donation is on the rise for older persons, as it is for all age groups. Living donor donation exceeded cadaver donation for the first time in 2001. The numbers of adult children donating kidneys to their older parents are increasing. Relatives, friends, church members and business associates are donating to older persons as well. The bodies of both prospective donor and recipient become the site of ethical judgment and activism about longevity and mortality (Kaufman, Russ and Shim 2006).

Though it occurs in much smaller numbers, liver transplant, including living donor transplant (in which a portion of the regenerative liver is removed from the donor), is on the rise for older adults as well. In 2008, 619 persons age 65 and over received a liver transplant, up from 29 in 1988 and 324 in 1998. The increase is enabled by expanding Medicare inclusion criteria along with improvement in transplantation techniques and immunosuppressive drugs and the training of more transplant surgeons. Liver transplantation was covered under Medicare beginning in 1996 for those with end stage liver disease other than Hepatitis B or cancer. In 1999, Hepatitis B was covered. Beginning in 2001, transplant for one form of liver cancer was covered as well. Other malignancies are under consideration for coverage currently.[2] Living donation is on the rise also. As living donation becomes normalized, more family members and friends of persons with liver disease ask about it and offer to donate.

Cancer treatments

Many cancers have become chronic illnesses today, manageable and sometimes curable because of the explosion in new, specifically targeted and less toxic treatments. Older patients who in the past did not receive treatments are now receiving them for several reasons. There is an unprecedented willingness of older cancer patients to undergo aggressive and long-term treatments, and they imbue those treatments with hope. The array of cancer interventions has become ordinary and routine. More people know about chemotherapy, radiation, surgery and drug treatments, have friends and relatives whose lives have been extended because of them and thus accept them as standard medical care, well into later life. Physicians do not want to deny therapies that may extend life, may make patients more comfortable or that could prevent or stave off disease recurrence. Finally, there is a growing interest among clinical investigators to include older persons in clinical trials and a growing awareness and desire on the part of patients to receive experimental treatments. As a result, (potentially) life-extending treatments have become routine into the eighth decade, and, in much smaller numbers so far, into the 90s. Yet there is controversy about how aggressively to treat cancers at older ages and doctors, patients, and families are often uncertain about how to proceed.

Beyond the use of treatments that render some cancers chronic conditions, the clinic sometimes makes a clear-cut dual offering to patients – aggressive, potentially life-prolonging treatment *and* palliative care that anticipates the end of life. This kind of choice is relatively new. It is perceived often by patients and families as a choice between ‘life’ and ‘death.’ Yet without medical guidelines or explicit discussions between doctors and patients about the (inevitable) end of life or toxicity of treatments, patients and their families have no basis on which to choose between these options, other than on the basis of hope embodied in aggressive interventions. It is no wonder that many patients (and families) proactively choose aggressive, toxic and costly treatments up until the time of death, even when clinicians also offer hospice care (Harrington & Smith 2008). Recent medical studies express a concern about the growing numbers of patients who receive aggressive chemotherapy treatments up until a few days and weeks before death, although the practice has been in existence for a long time.

Complicating medical success

Medicine will continue to be successful in extending older lives. Yet these examples point to the growing difficulty of defining medical success and ‘best treatment’ in an aging society. Evidence based medicine, together with an uneven and ironic societal ethics that does not want to deny treatment but excludes those without the resources to pay for it, insures that persons who can access all that medicine has available will be offered state of the art

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[2] http://optn.transplant/hrsa/gov/; http://www.cms.hhs.gov/mod/view.

interventions. And those interventions are difficult to refuse first, because it seems against medical progress and common sense to say ‘no’ to what quickly becomes standard of care, especially if interventions are immediately life saving; second, because current medical discourse emphasizes that refusing a procedure today may put one at risk later for death; and third, because hope is embodied in them.

At the same time, the successes of medicine exist both within a cultural milieu that emphasizes individual responsibility for colonizing the future through life planning and risk reduction and a socio-economic milieu of no limits but no safety net either. This complex situation provides the ground for the question posed above: *How much longer do I want to try to live, given what the clinic offers for my (potentially) life threatening condition?* Time left (days, weeks, months, years) and its worth come to dominate decision making. Thus persons turned patients, when faced with serious disease, often find themselves contemplating a calculus about how much *more* time they want to live given the options available to them: whether they want to try for *added* time; and whether any such additional time would be worth the effort and ramifications that treatments require, *given their age*. Because the value of life is neither age dependent nor quantifiable, that question is ever-present and open ended.

Though we have not yet arrived at “a time when the only limit on life span might simply be an individual’s decision to stop living” (Gupta, 2008:1) medical technique, the organization of Medicare reimbursement and clinical and consumer practices, together, already have shaped the ethical field in which U.S. residents dwell. The responsibility to authorize – or to attempt to authorize – the timing of one’s own ‘life’ and ‘death’ through palliative or aggressive treatment practices and in relation to the worth of potentially added time is, more and more in later life, integral to the clinical encounter. That responsibility remains one fundamental reason why debates about age-rationing remain lively and unresolved and why the cultural conversation about the end of life is loud, though far from clear.

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