

Virtual Mentor
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Ethical Issues in Geriatric Care

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FROM THE EDITOR

Medicine's New Breed of Patients

The shifting age distribution in the US has led to an increase in the geriatric population—those over 65—that will continue for nearly two decades. Physicians and other health professionals must rise to meet the challenges this new demographic presents. In the past, the medical community did not differentiate between the needs of adults in general and the needs of those in the geriatric population. In recent decades, however, it has become evident that caring for the geriatric population poses medical, social, and ethical issues that often differ from those posed by younger adults—they are living longer with more chronic conditions, they are more engaged in their own care, and they want medicine to help them remain healthy and active for longer than people of their age did in years past. Moreover, certain approaches of geriatric medicine run counter to the training and treatment orientation of physicians who have been in practice for some time. Goals in treating older adults, for example, include reducing medication, testing, and invasive procedures as much as clinically prudent. This issue of *Virtual Mentor* explores the questions that physicians must consider and resolve as they care for their recently reclassified “older adult” patients.

The ethics cases this month look not only at the elderly patient but at his or her caregivers. Confidentiality of the patient-physician encounter and respect for patient autonomy are foundational aspects of medical ethics. How can those principles be balanced against the well-being of caregivers, when a patient's decision directly—and adversely—affects the caregiver? What are the responsibilities of the physician to his or her patient and to that patient's caregivers? Those are the questions the first ethics case poses. David Barnard explains that, because caregivers are an integral part of a patient's care, physicians are obligated to advocate for their well-being, even if doing so means overriding a patient request. In a slightly different take on the situation, Mark J. Yaffe believes that respect for the patient's autonomy must supersede other concerns, so the patient must be convinced to consider his or her caregiver's well-being before the physician can intervene on the caregiver's behalf.

The second ethics case brings up the discomforting topic of age-based rationing. Haavi Morreim believes that age is far less important than other aspects of a patient's life and health in determining what services that patient should receive, and she questions the legality of age-based rationing. A second commentary provided by Ryan M. Antiel, David G. Zacharias, and Daniel E. Hall points to two examples in which end-of-life decision making took decidedly different courses. In one instance, futile interventions failed to save “John,” who had a massive ruptured abdominal aortic aneurysm and many comorbidities. In the second example, this one fictional,

Nathan decides to forgo treatments that would prolong but not improve his life and to “let death take care of itself.” These authors look forward to a time when there are more “Nathans” than “Johns.”

The third ethics case illustrates a common dilemma for those of us taking care of older adults—how to best honor a patient’s wishes when he or she is no longer able to make decisions and last expressed those wishes during a time of very different health status. Bernard J. Hammes and Thomas D. Harter comment on the importance of proper advance care planning and what physicians should do in its absence. Commenting on the same case scenario, Meera Balasubramaniam and Yesne Alici summarize the existing ethical guidelines for working through this challenging situation. Two opinions from the AMA’s *Code of Medical Ethics* offer guidelines on advance care planning and the consideration of quality of life when making treatment decisions at the end of life.

Becoming recognized as a specialty (the American Board of Internal Medicine began offering a certification of added qualification in geriatrics in 1988) does more than improve clinical care for the population the specialty serves. Specialty status brings the needs of that population to public notice. Mary Ann Forciea summarizes the twentieth-century history of geriatrics, which got its start in England. Jerry H. Gurwitz advocates for including older persons in clinical drug trials, inasmuch as the elderly comprise the largest number of beneficiaries of many drugs, particularly those for patients with cardiovascular conditions. And Richard Weinmeyer explains how recognition of the growing numbers of elderly in nursing homes has led to legislation to combat abuse in those homes. Richard G. Stefanacci gives an overview of Medicare means testing and tells what our society and policy makers must do in order to optimally apply means-based adjustments in fees for medical services.

But recognition as a group that deserves special clinical attention does not resolve all the medicine-related concerns posed by the aging baby boomer generation. This cohort of patients, Eva Kahana and Boaz Kahana say, has expectations of medicine and health care that older people of the past did not have. The present-day elderly have adopted health-promoting lifestyles, expect to share in decisions about their care, and demand their physicians’ personal attention, sometimes rejecting e-monitoring and other physician-replacing technology. Moreover, in “Who’s Responsible for Granny?” Carol Levine explains that our independence-valuing society, while ever-eager to help out in crises across the planet, offers strong resistance to suggestions that the public assist families in the financial and caregiving duties they face in caring for the elderly. In fact, says Nancy S. Jecker, the prevailing US culture of self-sufficiency and the attendant loathing of “becoming a burden” causes many old people to view “a good death” as one in which they don’t make demands on anyone. These elderly people feel there is a duty to die once one is no longer productive and independent. Jecker says emphatically: there is no duty to die.

Many of the questions raised and discussed in this month’s *Virtual Mentor* are just coming to public awareness. We don’t answer them here, but hope that the hard

thinking continues and that no one gives up searching for reasonable solutions. It's trite, but, if we are lucky, we will all be part of this patient group.

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ETHICS CASE

What Is the Physician's Responsibility to a Patient's Family Caregiver?

Commentary by David Barnard, PhD, JD, and Mark J. Yaffe, MD

Mr. McGuire lives at home with his only child, Jennifer. He is 75, has severe rheumatoid arthritis and a history of atrial fibrillation, for which he takes anticoagulation medication. He can no longer drive and, given his severe arthritis, is dependent on his daughter for his instrumental activities of daily living (IADLs), things like grocery shopping, paying bills, and managing medications, and some of his basic activities of daily living (ADLs), things like bathing, dressing, and walking. Jennifer has been his primary caregiver for two years and has had to cut back on her work hours and significantly decrease social outings.

Jennifer accompanies her dad on a visit to Dr. Peterson, his primary care doctor. As is Dr. Peterson's standard policy, he initially interviews Mr. McGuire alone. Knowing his patient's living situation and ever-increasing needs, Dr. Peterson raises the issue of respite care, as he has before. Mr. McGuire reaffirms his absolute opposition to the idea of leaving his home or having others come to help, even as a temporary measure, despite a long discussion about the potential long-term benefits of such an approach. He also asks Dr. Peterson not to even discuss this with Jennifer. After the initial interview, Dr. Peterson invites Jennifer into the exam room and continues with his interview and exam. As he probes deeper, he realizes that Jennifer is more tired than ever and perhaps depressed.

Dr. Peterson strongly believes that, if Jennifer doesn't get some relief, she may be unable to take care of her dad in the longer term. Forgoing respite care for Jennifer, he believes, could result in Mr. McGuire's placement in a long-term care facility, which is definitely not what Mr. McGuire desires.

Commentary 1

by David Barnard, PhD, JD

On the surface this case raises ethical questions of confidentiality (Dr. Peterson believes it is important to have an open discussion with daughter Jennifer about the growing burdens of Mr. McGuire's caregiving needs, but Mr. McGuire has forbidden him to raise the issue with her), and paternalism (Dr. Peterson believes it is in Mr. McGuire's own long-term best interest to override his refusal to consider additional home care services that would lessen the burden on Jennifer). Underlying both of these issues, however, is a deeper question: How should health professionals view the interests and concerns of their patients' family members who bear the burdens of long-term care for patients with serious illness or disability?

Traditionally, health professionals have seen the patient's family either positively, as a valuable resource in the care of the patient, or negatively, as holders of potentially conflicting interests from which the patient needs to be protected [1]. Either way, from this traditional patient-centric point of view families have no intrinsic value in themselves, but matter only instrumentally, that is, to the extent that they can be deployed as a resource or if necessary circumvented to serve the needs and preferences of the patient.

A common way out of the conundrum of potential conflict between the interests of the patient and his or her family has been to fudge it by declaring "the family as the unit of care." While this perspective—a central tenet of social workers, and particularly prominent in the rhetoric of hospice and palliative care—places important emphasis on the patient's wider social milieu, have we really faced up to the ethical complexities of that mantra? The issue of family caregiver burden is a useful lens through which to examine the question.

When we think of family caregivers, we might think of two contrasting realities. One is the gratification, pride, and self-esteem experienced by caregivers who derive meaning and fulfillment from their caregiving role. Family caregiving, influenced in important ways by culture [2], can express intergenerational reciprocity and mutuality in intimate family relationships. The other reality is the grim daily grind of exhaustion and loss of self that can overwhelm the isolated family caregiver [3, 4]. In thinking about family caregivers, both of these realities are important, and as health professionals weigh their loyalties, roles, and responsibilities in the care of people with serious illness and disability, both must be kept in view.

Mr. McGuire's heart disease and rheumatoid arthritis are typical conditions, but there are many others, e.g., disabling strokes, cancer, dementias such as Alzheimer disease. To mention these conditions is, in fact, to mention the leading causes of death in contemporary society. No longer do most people in the developed world die from infections, accidents, or other short-term catastrophes. We have conquered many infectious diseases; life is generally safer; and we can pull people through the immediate life-threatening aspects of many injuries or acute health problems thanks to our emergency medicine departments and intensive care units.

What happens to those of us who are kept from dying and then sent home needing close attention and care because of severe disabilities or chronic conditions is another matter. Our enthusiasm for life-saving and life-prolonging heroics is rarely matched by our attention or interest in the unglamorous, nitty-gritty work of long-term care [5]. And this poses serious challenges and questions for families, society, and health professionals.

Recent estimates are that 52 million caregivers provide care to adults with a disability or illness [6]; 43.5 million adult family caregivers care for someone 50 years of age or older and 14.9 million care for someone who has Alzheimer disease or other dementia [7]. Our society and our health system depend on this level of

informal caregiving, the economic value of which was estimated at \$450 billion per year in 2009, up from \$375 billion in 2007 [8]. Among the relevant systemic factors in the evolution of this dependence are:

- The massive shift toward outpatient care and deinstitutionalization;
- Pressures for early hospital discharge (the business plan and economic model for the modern hospital is the rapid turnover of beds to maximize reimbursement);
- Reliance on hospitalists who, while managing most hospital-based care, often do not know the patient or the family very well, leading to discharge plans that may reflect little knowledge of the actual situation at home;
- Fragmented social programs for home care that are a patchwork of federal, state, and local programs with barriers in the form of special requirements, preconditions, limitations, and caps;
- The low-status, low-pay, high-turnover nature of home health care (of nearly 2 million home care workers in 2013, almost 40 percent received government benefits, e.g., food stamps or Medicaid [9]), which diminishes the likelihood of a stable home health care workforce with the high levels of professionalism and morale required for this difficult and important job.

All of this shifts the burden of caring for the long-term disabled or chronically ill person to the family at home. Families are required to figure out the health care system, interpret and carry out treatment plans, negotiate with home health agencies and insurance companies, and do literal heavy lifting. Caregiving tasks and burdens can be complex and heavy: bathing or showering, dressing, feeding, toileting, lifting in and out of bed and chair, performing wound care and dispensing medications, maintaining pumps and other machines at the bedside, transportation, making calls to arrange care and services, dealing with insurance forms. One of the most comprehensive national surveys of family caregiving, carried out in 1998, revealed that:

- In 1997 nearly one in four adults provided care to a family member or friend;
- 20 percent of caregivers did so full-time or continuously;
- 41 percent had been caregivers for five years or more;
- One-third had been providing the most intensive kind of care (classified by the number of activities of daily living requiring assistance and hours per day of care needed);
- 26 percent were administering five or more different medications;
- 18 percent who gave meds reported having received no instruction in how to do so; and
- One-third reported no instruction on bandaging, wound care, or use of equipment [10].

Often, as in this case, these tasks come on top of running a household in the usual way (cleaning, shopping, preparing meals) and holding down a job. Furthermore, while gender roles have begun to even out with respect to family caregiving, women—wives, mothers, daughters, daughters-in-law—bear the heavier burden. To

paraphrase Nancy Guberman, in an article aptly entitled, “The Family, Women, and Caregiving: Who Cares for the Caregivers?” [11], it is often more women who initiate, coordinate, and assume many of the tasks of physical care along with housework and dealing with social services; change the diapers and do the laundry; get up 3 or 4 times a night for various tasks of care; comfort others (especially men) in times of crisis; worry that someone with failing short-term memory forgot to turn off the stove and run over to check; are distracted at work by thoughts, worries, and the need to plan complicated arrangements for care; and make excuses for others who do not do their fair share.

Underlying Dr. Peterson’s questions, then, about how to navigate between Mr. McGuire’s preferences and what Dr. Peterson perceives as their impact on Jennifer, are several further questions for families, society, and health professionals.

For Families

What are the obligations for caregiving that come with being a family member? Are there any limits to these obligations? Is it acceptable to say, “I can’t do this”—or “I don’t want to do this”? How should family members distribute the burdens of caregiving among themselves? What about promises to care that begin to be challenged by new realities? Are decisions to assume the unpaid, informal caregiver role genuine choices or the result of social conditioning, the absence of acceptable paid alternatives, or gendered divisions of labor reinforced by social policies or family structures?

For Society

As a society, we must decide what priority we place on the care of the dependent, chronically ill, or disabled? Can and will we organize the health care and social service systems in society with the flexibility, family-centeredness, and affordability required to help families do their part in this care [12]?

For Health Professionals

How should health care professionals view families? Is the traditional patient-centric ethic of the health professional—“my foremost loyalty is to the patient”—still appropriate? As bioethics scholars such as Hilde and James Lindemann Nelson [1] and John Hardwig [13, 14], have argued, the realities of long-term family caregiving require us seriously to entertain an approach to the ethics of health care that places more weight on family interests. Hardwig [13] argues that an exclusively patient-centered ethics must be abandoned because it is patently unfair to other family members. The patient’s health-related needs are often important enough to override the interests of family members in treatment decisions, but not always. In proxy decision making, Hardwig argues (against the grain of bioethics orthodoxy and the weight of both legislative and judicial precedent), surrogates should be instructed to consider the interests of everyone affected by treatment decisions, including their own. Family members’ interests are relevant in proxy decisions not because the patient may have had them in mind, but regardless of whether he or she had them in mind. Hardwig posits that, while proxies must guard against undue emphasis on their

own interests, undue emphasis on patients' interests should also be avoided [14]. It is irresponsible and wrong for competent patients to make self-centered or exclusively self-regarding treatment decisions if these decisions deny fair and equitable consideration of legitimate interests of all concerned.

Recommendations

Notwithstanding the presumption of professionals' obligation to respect patients' autonomy, it is appropriate for health professionals to argue against patients' choices when patients' exercise of autonomy comes at too great a cost to their families. While we generally allow competent individuals to make their own decisions, including how (short of abuse or neglect of minor children or the elderly) to treat members of their own family, Mr. McGuire's choices in this case are no longer a purely private affair. Mr. McGuire's insistence on continuing to rely exclusively on Jennifer for the care and support he needs at home is placing unreasonable and unfair demands on her, and for Dr. Peterson to acquiesce to Mr. McGuire's insistence that he avoid broaching the subject with Jennifer would make Dr. Peterson complicit in this unfairness. Dr. Peterson should tell Mr. McGuire that, notwithstanding Mr. McGuire's wishes, he cannot refrain from convening a family conference to begin to explore a more sustainable balance between Mr. McGuire's and Jennifer's needs.

We should not assume that Dr. Peterson will know the right answer to a family's question about how much well-being, health, or hopes for the future should be sacrificed for the care of the neediest member. But we should expect that health professionals will be alert to these questions and view it as one of their ethical responsibilities to help families sort out the complicated balancing of interests that come into play when someone is seriously ill, disabled, or dying, as well as to advocate for social policies that might minimize a family's avoidable burdens.

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Commentary 2

by Mark J. Yaffe, MD

This case describes a common occurrence in the management of chronic illness, specifically the ability to address the needs of both the care receiver and the caregiver. When they are both looked after by the same primary care physician (PCP), the doctor has a fiduciary responsibility to each one, despite the possibility of conflict of interest. Since a comparable dilemma exists when a PCP provides care to spouses who may be in conflict for any reason, some PCPs have acquired a spectrum of strategies they hope will be useful in such delicate (and stressful) situations.

When a PCP looks after a care receiver and not the caregiver, given the possible enmeshment of the two, the PCP may not be able to provide comprehensive care to the former without some interaction with the latter. Or, framed another way, why wouldn't it be good medical practice to routinely involve the caregiver? Indeed, in the United States the Health Insurance Portability and Accountability Act (HIPAA) of 1996, while protecting the privacy of patients, permits family members or others directly involved in the patient's care to be present during medical visits or informed about a diagnosis, treatment, or future plans, unless the patient specifically objects [1, 2].

Given the potentially complex nature of the doctor-patient-caregiver triad, however [3], a challenge exists in ensuring patient autonomy in such cases. As discussed below, addressing this goal does not, however, preclude respectful attempts by a PCP to provide patients with opportunities to see the perspectives, viewpoints, or needs of others.

In a study of Canadian urban-based family physicians (FPs) that Jacqueline Klvana and I conducted, 81 percent of the FPs surveyed reported finding encounters with

family caregivers stressful. As few as three such encounters per day were sufficient to result in reported stress [3]. In that study, when the FPs were asked to rank 17 factors that impact on the doctor-patient-caregiver triad, the second most commonly cited concern about the “triad encounter” was caregivers and care receivers with differing agendas and needs. This was a concern for 63.4 percent of the FP respondents. Hence it is easy to imagine the feelings of Dr. Peterson in the aforementioned case.

It has been suggested that physicians require more and broader training about issues pertaining to caregiving [4]. This would include the general principle that visits that incorporate both caregivers and care receivers might flow better if PCPs encouraged them to try to discuss beforehand the matters that will be brought up during the medical encounter. In the case of Mr. McGuire and Jennifer, such an approach may not be helpful initially, since we are given no indication that Jennifer is aware of her growing need for respite.

Dr. Peterson might consider structuring his encounter with Mr. McGuire and Jennifer around the goal of defining care more broadly. He could summarize Mr. McGuire’s health status and limitations, but reframe them by introducing the concept of the Chronic Care Model (CCM), explaining that in this approach both patient and family member(s) join him as part of the treating team [5-7]. Dr. Peterson might elaborate on some advantages of this model, including the opportunity for expanded input on care options and for hearing different perspectives on a treatment plan.

Dr. Peterson could acknowledge that in the CCM there is potential for conflict arising from differences of opinion, feelings, or needs, and that he is comfortable hearing such conflict. While the doctor might in fact not be so comfortable early on, as a member of a collaborative care team he should strive to be as open to different approaches as he would like the caregiver and care receiver to be. Following this sort of overture, Dr. Peterson might close the visit by suggesting that caregiver and care receiver try to reflect, between then and the next visit, what the CCM might mean for each of them.

Dr. Peterson might schedule the subsequent visit a little sooner than usual in order to follow-up on the discussion. At that encounter, initially with Mr. McGuire alone, Dr. Peterson might ask for his reflections on the last visit. Given Mr. McGuire’s previous resistance to the idea of respite care and the reasons for it, one might expect him to verbalize some appreciation for certain aspects of the CCM, but to assert his right to control and decision making. Dr. Peterson should validate this feeling, but perhaps note that Mr. McGuire’s permitting his daughter to be present for the second part of each visit suggests his tacit acknowledgement of the importance of her involvement. This would provide an opening for Dr. Peterson to say to Mr. McGuire, “I am actually worried about your daughter. The last few times you two have been here, she has not been looking well. What do you think?”

This sort of approach would generally provide a doctor a natural opportunity to accentuate the significant contributions made by caregivers. Without specifically raising the issue of respite care, introducing the topic of caregiving could facilitate a discussion about the common problem of what is called “caregiver burden,” which may have negative implications for both caregiver and care receiver [8]. If Mr. McGuire did not agree with Dr. Peterson’s concerns about Jennifer, the doctor might broach having Jennifer take the Brief Assessment Scale for Caregivers (BASC), an empirically derived measure of caregiver burden with good internal reliability and both construct and criterion validity [9]. He could say something like, “Given how common it is for caregivers to get run down and exhausted, I’m wondering whether this may be happening to Jennifer. There is a short paper test to find out. What would you think if I asked Jennifer to fill out this questionnaire?”

Dr. Peterson’s more direct approach in bringing up Jennifer’s health might prompt Mr. McGuire to voice worries, fears, or misconceptions about respite care (e.g., that it might open the door to long-term placement). Each specific concern could then be validated and addressed with specific patient-centered solutions, which may require the assistance of a social worker familiar with respite care. It may be necessary to appeal to Mr. McGuire’s self-interest by reminding him that Jennifer may be able to provide better and longer-term care if her needs are respected and addressed. If Mr. McGuire continues to refuse to acknowledge the possibility of strain on Jennifer, it might help to put him in contact with a care recipient from his or a colleague’s practice who had been in a similar position and had benefited from respite care.

Another approach would be one that draws on principles of couples’ therapy, asking Mr. McGuire if Dr. Peterson can facilitate a discussion about each party’s needs. If he consents, and Jennifer is forthright, this would allow the father to hear his daughter’s own words of distress. Many caregivers need a structured, supportive forum in which to openly vent that, despite their love and commitment to caring, there may be limits to their abilities to support some of the care recipients’ needs or wishes. The honest expression of feelings and needs sometimes becomes the stimulus to a more open recipient-caregiver relationship in that other issues not previously discussed may more easily come to the surface [10].

Should Mr. McGuire continue to refuse any discussion of Jennifer’s situation, Dr. Peterson might send Jennifer a note with a list of community resources for family caregivers and the suggestion that she seek help from her own PCP, a social worker, a psychologist, or other therapist.

The aforementioned interventions may be time-consuming or stressful for PCPs. Some may argue that a social worker should handle all these discussions. However, the potential to be an instrument of growth for a person with chronic illness, the opportunity to foster a more realistic and open dialogue between caregiver and care receiver, and the possibility of a richer doctor-patient relationship should encourage PCPs to address these issues to the extent of their skills and time availability.

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ETHICS CASE

Should Age Be a Basis for Rationing Health Care?

Commentary by Haavi Morreim, JD, PhD, Ryan M. Antiel, MD, MA, David G. Zacharias, MD, MPH, and Daniel E. Hall, MD, MDiv, MHSc

Dr. Rossi, an orthopedic surgeon, was recently selected to be a voting member of one of the FutuRx Health Maintenance Organization's (HMO) committees, which is solely responsible for determining covered and excluded services for the various FutuRx HMO plans.

The focus of one of the committee meetings was exclusionary criteria for coverage of replacement arthroplasty. During this meeting, a committee member proposed an absolute cutoff age of 90 for the surgery, according to the rationale that, given the median lifespan of the US adult population, a 90-year old person would not live long enough after the surgery to justify the expense. Proponents of the proposal argued that the cost savings from this exclusion could be shifted towards lower premiums and more comprehensive coverage for others. This particular proposal resulted in a lively discussion among the committee members. There were many valid points raised for and against this proposal, but all Dr. Rossi could think of was his patient, Mr. Turner.

Mr. Turner is 91 years old and a former Olympic marathon runner. He has been seeing Dr. Rossi for his severe right-knee osteoarthritis but is otherwise in excellent health. Even though Mr. Turner continues to enjoy an active life, over the past 6-9 months, the knee pain has limited his ability to do what he loves most, run. Mr. Turner ran his last full marathon 1 year ago and, even with his severe osteoarthritis and advanced age, was able to complete it in less than 4 hours and 45 minutes. Since then, due to his knee pain, Mr. Turner has had to decrease the frequency and the intensity of his runs and more recently has been unable to run at all. Dr. Rossi remembers his multiple conversations with Mr. Turner about how much running means to him and how much enjoyment he gains from this particular activity. Dr. Rossi was considering a knee replacement for Mr. Turner and, even though proposed changes will not affect Mr. Turner directly (he is not part of FutuRx HMO) Dr. Rossi feels uneasy voting for a change that would restrict patients like Mr. Turner from getting a procedure that, in some circumstances, has a high potential for increasing quality of life. On the other hand, Dr. Rossi appreciates the value of limited health care dollars, the larger impact of such cost-saving approaches, and the biological limit on the years of benefit patients like Mr. Turner would gain from undergoing joint replacement.

Commentary 1

by Haavi Morreim, JD, PhD

Fair warning: as the daughter of a healthy, active 99-year-old father, and as a baby boomer who decided long ago that surely middle age does not begin until at least age 60, I bring a certain bias to the conversation. Still, I am younger than Mick Jagger and always will be. That being said, I believe Dr. Rossi's question can be addressed along several dimensions.

Thoughtful commentators have proposed that yes, age does matter when it comes to allocating scarce resources in health care. Bioethicist Daniel Callahan, for instance, proposes that there is such a thing as a natural life span, a full life, and that it may not always be wise to keep “elderly people with chronic diseases expensively alive” [1]. He noted that, as baby boomers retired, Medicare outlays were expected to grow from 3.5 percent of the gross domestic product to 5.8 percent by 2038 [2]. Hence, we must take seriously the idea of age-based limits on medical care. The proposal will be explored along several dimensions: economic, ethical, empirical, and legal.

First, the economics and ethics of scarcity. “Fiscal scarcity” (the general reality that finances are limited, and that we simply cannot afford to provide every health care intervention of conceivable benefit) often seems less pressing than “commodity scarcity” (the absolute shortage of some item, usually a physical object such as organs for transplant or available ICU beds) [3]. With commodity scarcity there is the consolation that, if one patient does not receive the available item, some other patient will. With fiscal scarcity it is tempting to ignore the budget for someone who needs something extra: it's just money, after all, and surely this person's health is more important.

The failure to implement reasonably clear limits on health care spending is a recipe for relentlessly rising expenditures—a familiar phenomenon in US health care. Arguably it has also contributed to our hesitancy to extend health insurance to millions of uninsured people. If spending for the insured is out of control, how can we add so many more people to the pool?

An HMO like FutuRx has obligations to all its members, whose financial contributions comprise the resource pool from which individual needs are then served. That pool must be managed so that the members as a whole can receive the spectrum of benefits they legitimately expect, without permitting excessive demands of a few to deplete unduly what is left for the many. This “contributive justice” [4] becomes increasingly important in the wake of the Affordable Care Act, which hopes to extend health care coverage to millions of uninsured people, many of whom have chronic conditions that previously rendered coverage unavailable or unaffordable.

Cost-conscious resource policies, however, must be medically as well as ethically justified. We turn to empirical factors, because good ethics begins with good facts. Age is at best a crude predictor of medical utility, because people in any age group

differ markedly. Life expectancy varies by gender and by racial group, for instance [5], as well as by underlying health condition.

The Social Security Administration's calculator for life expectancy says Mr. Turner as a 90-year-old man can expect to live another 3.8 years [6]. However, this figure is likely conservative, as it takes no account of the fact that he has no other known health issues, such as heart disease, diabetes, or hypertension—common conditions among his age peers. Thirty-five years ago, at age 65, his life expectancy would have been in the mid-80s [7]. Turner put that number in the rear-view mirror long ago, as one of the healthier members of his cohort. He could live another 15 years.

Thus, it makes less medical sense to focus on age as such than to inquire which factors actually influence longevity of total knee arthroplasty. Preoperative physical function appears to be significantly associated with postoperative outcome, along with such factors as higher education level, higher socioeconomic status, and lower comorbidity [8, 9]. Although the average age of subjects in these studies was distinctly less than 90, age was not identified as a significant component.

Consider also the consequences of failing to intervene. For a healthy, active patient like Mr. Turner, joint replacement could not just lead to a better quality of life, but could potentially avoid costly medical problems such as loss of strength and bone density from markedly reduced activity, leading to problems like fractures with prolonged hospitalization.

Close attention to such medical details lies the heart of the guidelines on which health care increasingly relies to produce evidence-based care and outcomes and to use resources as efficiently and effectively as possible [10]. It is difficult to argue that, medically, economically, or ethically, it is wise to ignore science and rely instead on crude placeholders such as age.

The implications stretch further. Life expectancy tables are a function of gender and race as well as age. If FutuRx decides to set an age threshold for joint replacement, it must logically vary that threshold for race and gender as well as age. Black males, Hispanic women, and white males and females could thus have different cutoffs of eligibility for that as well as other medical investments.

This unsavory specter brings us to legal issues. The Age Discrimination Act of 1975 (the "Age Act") provides that, with certain exceptions, "no person in the United States shall, on the basis of age, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any program or activity receiving Federal financial assistance" [11]. The statute is enforced by the Office of Civil Rights, and it carries detailed regulations for implementation [12, 13]. The Affordable Care Act reemphasizes the illegitimacy of age-based discrimination [14].

Age Act regulations expressly apply to organizations that provide health care [15], stating that, barring certain exceptions, such organizations cannot use age

distinctions to deny someone the benefits of any program, service, or activity receiving federal financial assistance. Medicare would seem to be such a federal financial assistance program, and an HMO with Medicare patients would seem to qualify as such an organization.

The regulations provide examples, including one that directly illustrates FutuRx's potential legal trouble. Suppose a local health department refuses to train anyone over 65 to perform CPR, on the assumption that older people lack the strength to perform it [16, 17]. This age-based rule would fail because, although physical ability may be a proper criterion for eligibility to learn CPR, age does not capture physical ability very well. Moreover, physical ability can be measured directly. Age thus could not stand as a proper surrogate for physical ability, and so the age cutoff would violate federal law.

By implication, if FutuRx forbids anyone over 90 to receive total knee arthroscopy, on the assumption that age can suitably stand as a surrogate for likely duration of joint survival, FutuRx would have to show the government that a prognosis for joint survival cannot be directly measured and that age is a legitimate surrogate. FutuRx will likely fail. As discussed above, we already know direct prognostic measures such as preoperative activity level, educational level, and the like. We don't need age as a surrogate marker.

Hence, FutuRx's proposed policy would likely be unlawful. It would probably also be politically inept. During the 1990s, HMOs enacted a wide variety of cost-containment measures, often crudely drawn and implemented. Many of them turned out to be medically and even economically unwise (e.g., gatekeeper arrangements forbidding patients to see a specialist without a prior visit to the primary physician), and the whole situation led not only to widespread system gaming, but also to a huge political backlash and a rollback even of many legitimate cost-containment mechanisms.

FutuRx would be well-advised to reject an age cutoff for joint replacement.

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Commentary 2

by Ryan M. Antiel, MD, MA, David G. Zacharias, MD, MPH, and Daniel E. Hall, MD, MDiv, MHSc

Given the strain that health care costs have placed on the US economy, there has been renewed attention on exclusionary criteria for coverage of various procedures and services. Age is an obvious, albeit controversial, independent exclusionary criterion to explore. This case poses the question of a knee replacement for a 91-year-old marathon runner. This is not a common occurrence; the majority of health care spending is for patients who are in their final year of life, and often in their last couple of months. For example, one of us took care of John, a 91-year-old man with a massive ruptured abdominal aortic aneurysm and multiple comorbidities who was rushed by ambulance to the hospital. At his family's request, John underwent surgical repair and was subsequently transferred to the ICU where he remained persistently unconscious on a ventilator with an abdomen full of blood, only to die two weeks later despite continued rescue efforts costing tens of thousands of dollars.

John's familiar story illustrates how health care resources are consumed by intensive rescue efforts at the end of life. From 1960 to 2000, the individual rate of health care spending on those aged 65 and older increased over twice as much as spending on the general population, yet the incremental cost per year of life gained at 65 was four times greater than the incremental cost per year of life gained at birth [1]. In other words, in the last 40 years the United States has spent proportionately more money per capita on the elderly with proportionately less return for that investment. Indeed, the financial solvency of the United States (and other developed nations) requires that we identify and confront the source of these problems [2, 3].

One source is the expectation that science and technology will eventually triumph over sickness and death. Since at least the time of Francis Bacon (1561-1626), medical practitioners and patients have acted on the hope that, if given enough time, science could one day eliminate disease and suffering [4]. The fabulous success of this "Baconian project" is undeniable. Medical technology has increased the number and quality of the years we live. Patient and practitioner alike have become more resolute that the powers of medical science and technology have no limit, and some scientists reinforce this expectation by arguing that it is only a matter of time before death becomes optional.

This prediction of a technological utopia is often dismissed as science fiction, but the fiction is compelling nonetheless. We struggle to know when or how to limit technology as death approaches because the fiction of an optional death lulls us into believing that we can delay the inevitable. Yet death remains an absolute and

unavoidable limit. As Atul Gawande notes, “Our medical system is excellent at trying to stave off death with eight-thousand-dollar-a-month chemotherapy, three-thousand-dollar-a-day intensive care, five-thousand-dollar-an-hour surgery. But, ultimately, death comes, and no one is good at knowing when to stop” [5].

The tension between medicine’s utopian promise and its limited resources is made apparent by the necessity of health care rationing. Ability to pay remains the de facto criteria for rationing in the United States, and such rationing happens every day, though most Americans don’t recognize it as such. Well-intentioned attempts to develop more equitable criteria for rationing typically falter because rationing done by someone to someone else elicits fear of tyranny, such as the false reports of “death panels” in the Affordable Care Act of 2010 [6]. However, ethicist Daniel Callahan points to an alternative approach to rationing that may be more constructive. He exhorts the profession to help people “live out a full and natural life span, not simply more life without discernible end” [7].

Wendell Berry offers a vivid example of what this kind of health care rationing might look like in his novel *Hannah Coulter* [8]. Hannah’s husband, Nathan, returns from World War II to the township of Port Williams, Kentucky, where he takes up farming just as his father and grandfather did before him. Together, Nathan and Hannah care for the land entrusted to them, and from their faithful stewardship grows a bountiful life that is well-lived, full of hard work, and embedded in a community of friends and family who love their land and each other. But in the end Nathan falls sick, very sick. He isn’t a “doctor-going” type of man, so his family has to beg him to see the specialist in Louisville who diagnoses advanced cancer with poor prognosis. Not knowing what else to say or do, the specialist recommends intensive therapy. “It was a story we all knew,” reflects Hannah, “one that has been lived and told too many times in Port William, a bad story” [9]. But rather than scheduling chemotherapy, Nathan stands up, shakes the doctor’s hand, thanks him for his time, and walks out.

Nathan has known he is dying for quite some time, but Hannah needs time to adjust. “Well, what are you planning to do? Just die? Or what?” cries Hannah. “Dear Hannah,” Nathan replies, “I’m going to live right on. Dying is none of my business. Dying will have to take care of itself” [10]. Over time Hannah begins to understand: “He wanted to die at home. He didn’t want to be going someplace all the time for the sake of a hopeless hope. He wanted to die as himself out of his own life. He didn’t want his death to be the end of a technological process.” So Nathan goes on living at the farm with his family and community around him until the end. “He was not false or greedy. When the time came to go, he went” [10].

Nathan’s approach to health care rationing among the elderly avoids the tyranny of “death panels” because Nathan chooses it for himself, even to the pain of his wife, Hannah. The source of his empowerment is not rooted in “autonomy,” but in a thick understanding of a life well-lived. Nathan has accepted death long before it comes.

And when it does come, it is the fitting and proper end to the narrative of his life. He goes on living and leaves death to take care of itself.

Most clinicians probably have experience with patients like Nathan, but the story of John's death at the beginning of this essay is more typical. Any approach to rationing that addresses the false promises of utopian medicine peaceably will require discourse within medicine and society that produces more Nathans and fewer Johns. How this might transpire is not clear, but at the least it will require scrutiny of the entire system we have created [11]. Rather than running yet another randomized controlled trial to test the incremental increase in effectiveness of the newest lipid-lowering agent or retrospective study to ascertain the maximally cost-efficient mode of health care delivery, we might rather invest in understanding how medicine might support thicker descriptions of what it means to live well. And most importantly, we need an understanding of how a good death fits within the narrative of a life well-lived.

Whether medicine will be able to recover a substantive language for public discourse on what it means to die well remains to be seen. Callahan points out that:

the greatest obstacle may be our almost utter inability to find a meaningful place in public discourse for suffering and decline in life...we have created a way of life that can only leave serious questions of limits, finitude, the proper ends of human life, of evil and suffering, in the realm of the private self or of religion; they are thus treated as incorrigibly subjective or merely pietistic [12].

While it would be great if we could build consensus about the proper ends of human life and the scope of medical technology from universally persuasive principles, that utopian ideal is just as much of a fiction as "optional death." But the stakes are too high to kick the can called "rationing" down the road for another generation. The available resources for the necessary conversation may be subjective, but they are the only resources at hand [13]. Perhaps our meager subjectivities and pieties may be sufficient to begin the necessary conversations in our homes, communities, schools, hospitals, and businesses—conversations that might lead more people to know themselves and the limits of medicine like Nathan Coulter who rationed his own medicine so that he could keep on living until it was time for him to go.

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ETHICS CASE

Questions about an Advance Directive

Commentary by Bernard J. Hammes, PhD, Thomas D. Harter, PhD, Meera Balasubramaniam, MD, MPH, and Yesne Alici, MD

Mrs. Erickson lives in a long-term care facility. At 72, she has hypertension, mid-stage Alzheimer disease, and aortic stenosis complicated by congestive heart failure. It has become challenging to manage her fluid balance on an outpatient basis. When she was admitted to the inpatient teaching service from the dementia unit of her care facility with acute decompensation due to heart failure, an echocardiogram indicated that her aortic stenosis had progressed to a severe stenosis stage, and she was admitted to the hospital. Mrs. Erickson is able to interact with caregivers intermittently and is able to participate in her activities of daily living (ADLs), although she requires assistance with all of them.

Mrs. Erickson has a 15-year-old advance directive in which she indicated that, should she not be able to make decisions about her care, she wanted the benefit of all available medical interventions to preserve her life. At the time the advance directive was prepared, Mrs. Erickson had mild hypertension that was fairly well controlled with dietary changes, and no signs of Alzheimer disease. She was living alone and working full-time and named her only daughter as the person with durable power of attorney for health care.

Shortly after Mrs. Erickson entered the care facility seven years ago, her daughter died, so that now her 19-year-old granddaughter, Caitlin, is her next of kin. Caitlin was not mentioned in Mrs. Erickson's advance directive, and she says that she and her grandmother have never discussed end-of-life care.

After a thorough presentation of Mrs. Erickson's history and status by the intern of the team, the attending physician suggested offering her an aortic valve replacement as a therapeutic option. This sparked lengthy discussion among the team members, who finally decide to discuss the options with Caitlin. The resident on the team, Dr. Marx, felt ill at ease about the prospect of surgery. Even though the patient clearly indicated that she wanted all interventions, Dr. Marx thought that, if she could make this decision in her current state of health, she would choose not to pursue this route.

Caitlin came in for the discussion of the risks and benefits of various options. After hearing what the team has to say, she sighed. "This is a really tough decision. Frankly, I'm not sure what to do. Do you think surgery is the best option?"

Dr. Marx does not know how to respond; the patient has a clear clinical need for surgery and previously indicated that she wanted everything done to preserve her life. Yet he believes she would not choose that option in her current state of health.

Commentary 1

by Bernard J. Hammes, PhD, and Thomas D. Harter, PhD

We will comment on two aspects of this case. First, we will discuss why we think this case is an example of poor advance care planning. Second, we will discuss how we would move this case forward via an ethics consultation.

It is our opinion that not all advance care planning programs are equally beneficial to patients. In our experience good advance care planning programs have at least two features: (1) they have processes and systems in place to help people thoroughly reflect on and communicate their values, preferences, and goals of treatment, including a discussion about what circumstances would change a person's goals from wanting full treatment with a curative intent to wanting comfort measures that aim only to ease the dying process; and (2) they are responsive to changes in a person's medical condition over time. When people undertake advance care planning that does not include these features, the plans they create are at risk for being ambiguous and causing confusion rather than clarity for third-party treatment decision makers.

We infer that Mrs. Erickson's advance care planning process was poor because these two features are absent from the case description. Regarding the first feature—reflection on and communication of values—it is unclear what she means by wanting “the benefit of all available medical interventions to preserve her life.” Did she mean “all medical interventions” regardless of their predicted success, or would she reject treatments that she considered overly burdensome? By “preserve her life,” did she mean being alive, being conscious, both, or something else? Regarding the second feature—responsiveness to changing health status—Mrs. Erickson's advance directive appears not to have been updated since it was first completed when she was living independently and was significantly healthier than she is now. The failure to work with Mrs. Erickson to update her advance directive at any point at which her health notably changed—such as when her hypertension progressed to congestive heart failure, when she developed Alzheimer disease, or when she could no longer independently care for herself—calls into question whether her advance directive is still an accurate reflection of her wishes.

The situation occasioned by this faulty advance directive is doubly ironic: first, a document intended to guide Mrs. Erickson's treatment has effectively hindered the decision-making process it was supposed to clarify. Since her advance directive was completed when Mrs. Erickson was still in relatively good health and living independently and was never updated, it is unclear whether she would still want full treatment in her current, declining state of health. Second, the ethics consult necessitated by this lack of clarity may result in an outcome that Mrs. Erickson might have opposed if she still had decision-making capacity.

To resolve this case via an ethics consultation, we begin with the facts. We know that Mrs. Erickson's granddaughter, Caitlin, does not know her values, wishes, or goals of care beyond what is stated in her advance directive. We also know that Mrs. Erickson's advance directive may not reflect her current values and treatment preferences. Furthermore, we know that Mrs. Erickson's current baseline functioning involves intermittent interaction with others and that she needs assistance with all her daily living activities. We also presume that Mrs. Erickson's treatment team—as the inpatient teaching service—would not be the team that performed the aortic valve replacement surgery.

Two pieces of information must be gathered at this point. First, we do not know the extent to which Mrs. Erickson is interactive and able to participate in treatment discussions. When a patient lacks treatment decision-making capacity, he or she lacks the ability to understand and reason with information pertinent to making a treatment decision [1]. Lacking this ability, though, does not mean that patients necessarily have lost the ability to have or communicate their values, goals, and treatment preferences, such as what gives them pleasure, what fears they have about their illnesses or injuries, or what outcomes they hope treatment will achieve. It might be the case that Mrs. Erickson cannot engage in any meaningful communication and that she only answers questions in gibberish. However, if Mrs. Erickson is somewhat communicative, she might be able to express basic preferences or values that can guide, or at least help contextualize, treatment decision making. For example, she might tell the treatment team that her greatest pleasures in life are daily walks outside and eating fried foods—values that appear to contradict surgery. Conversely, she might state that all she wants is to live a long life regardless of where she resides—a preference that appears to indicate surgery.

Second, we do not know the scope of the granddaughter's decision-making authority. If Caitlin were Mrs. Erickson's power of attorney for health care, she would have the authority to make treatment decisions that she believes are in Mrs. Erickson's best interests. However, in the case as described, Caitlin is neither Mrs. Erickson's power of attorney for health care nor her legal guardian. Caitlin's authority to make treatment decisions for Mrs. Erickson will therefore depend on the laws of the state where Mrs. Erickson is being treated [2]. For example, some states, like Ohio, legally recognize a hierarchy of treatment decision makers for patients without either a power of attorney for health care or a legal guardian. Other states, like Wisconsin, do not have such treatment decision-making hierarchies.

As respect for patient autonomy has become a common fixture in treatment decision-making processes, it is ethically obligatory for physicians to offer and provide treatments that accord with patients' known preferences. However, physicians in the United States also have professional, ethical, and legal responsibilities to maximize patient well-being and minimize patient suffering. Treatment decision making is thus based on a combination of patient preferences and sound medical judgment.

That the resident in Mrs. Erickson's case believes she would not want surgery is irrelevant in our assessment because it appears to be based on his subjective interpretation of Mrs. Erickson's quality of life. If the resident had good reasons to believe that Mrs. Erickson did not want to have surgery, then perhaps his belief would have some merit. Depending on the state where this case occurs, there may be laws prohibiting treatment decisions based on perceptions of a patient's quality of life that are not specifically directed or indicated by the patient. Wisconsin law, for example, prohibits the withholding or withdrawal of effective life-sustaining treatment unless the patient is in a persistent vegetative state, has clearly known preferences to forgo such treatment, or has appointed a power of attorney for health care [3].

Based on this understanding of Mrs. Erickson's case, we would make five broad recommendations:

- Clarify Mrs. Erickson's granddaughter's decision-making authority and include Mrs. Erickson in treatment discussions to the extent that she is able to participate.
- Given the lack of clarity about Mrs. Erickson's current treatment preferences, immediate treatment decisions should be based on medical necessity. Mrs. Erickson's treatment team should consult with the cardiothoracic surgery team to determine both the feasibility and urgency of surgery; if the surgery team recommends against surgery, it should be explained to Mrs. Erickson and her granddaughter why surgery is not a viable therapeutic option. In making a recommendation about surgery, the surgery team should consider whether surgery will help sustain Mrs. Erickson's life or merely prolong her dying process.
- If surgery is a viable option and is urgently needed, Mrs. Erickson should receive the surgery since we cannot say with certainty that she would not want it. However, if surgery is not urgent and there is time to explore Mrs. Erickson's treatment preferences further, surgery should be withheld as long as needed to explore her treatment preferences. The treatment team should attempt to identify whether there are others who know Mrs. Erickson—e.g., friends, nursing home residents, or staff—who may have had specific discussions with her while she was cognizant or who might be able to offer insight into her values or goals of care to help clarify her treatment wishes.
- If surgery is not a viable option, the treatment team should consider other treatment options including the possibility a comfort-only focus, in which treatment is offered with a purely palliative intent. If available, the treatment team should consider consulting with their affiliated palliative care or hospice providers.
- The resident concerned about offering surgery to Mrs. Erickson should bring this instance of poor advance care planning to the attention of the quality department or ethics committee and help them redesign the system so that it becomes part of the institutional culture to routinely update and rediscuss patients' preferences, particularly when new, progressive health conditions

are diagnosed or when these conditions might affect the long-term capacity of patients to make their own health decisions.

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Commentary 2

by Meera Balasubramaniam, MD, MPH, and Yesne Alici, MD

At the outset, this might appear like a straightforward situation of implementing what the patient has specified in her advance directive, but critical elements of this case raise ethical dilemmas for both the care team and Mrs. Erickson's granddaughter. Firstly, it is important to note that Mrs. Erickson's advance directive was prepared 15 years ago, when her medical condition consisted only of mild, well-controlled hypertension. More importantly, she is reported to have been significantly more independent and capable than at the present. Secondly, while we are informed that the granddaughter, Caitlin, is her next of kin, Caitlin and her grandmother have not discussed end-of-life care, so her lack of awareness of Mrs. Erickson's goals and values is of concern.

Guidelines and Recommendations

Decision-making capacity. It is paramount to first determine whether Mrs. Erickson has the capacity to make a decision regarding her treatment. This is critical, because advance directives or surrogate decision makers come into play only if the patient lacks capacity. Miller and Marin's formulation for determining decision-making capacity consists of the following questions: (a) Do the history and physical

examination confirm that the patient can communicate a choice? (b) Does the patient understand the essential elements of an informed consent? (c) Can the patient assign personal values to the risks and benefits of an intervention? (d) Can the patient manipulate the information rationally and logically? (e) Is the patient's decision-making capacity stable over time [1]?

While individual clinicians may vary in the specific questions they ask a patient, it is recommended that the elements of understanding, appreciation, reasoning, and expressing a choice be covered for each decision made, for a person may have the capacity to make one decision but not another [2]. Although cognitive impairment impacts one's ability to understand and express, it does not automatically preclude decision-making capacity. Sessums and colleagues demonstrated that the mini-mental status exam (MMSE) correlates with capacity or incapacity only in extreme scores [3]. Palmer and colleagues identified the ability to conceptualize, initiate, and persevere on a thought as key factors indicating capacity to appoint a proxy, while memory was a significant predictor of capacity to consent to a neurosurgical clinical trial [4].

We recommend first discussing her medical situation thoroughly with Mrs. Erickson. This ought to include details of her medical condition, the goals of treatment, description of the available treatment options, the prognosis of her condition in the case of each treatment option, the chances of success and risks involved in the case of each treatment modality, the expected quality of life related to each option offered. She should be allowed the opportunity to ask questions. After this discussion, the next step would be assessing Mrs. Erickson for her capacity to make a decision regarding whether or not she wants to undergo aortic valve replacement. If an attending physician determines that Mrs. Erickson has the capacity to make a decision regarding the proposed surgery, the decision she makes at this time should be honored, irrespective of whether it is consistent with the advance directive. This would be served best in a multidisciplinary team meeting, with her granddaughter present, if Mrs. Erickson desires. It would also be good to revisit Mrs. Erickson's advance directive now if she possesses the capacity to do so.

Should Ms. Erickson be deemed to lack capacity, we recommend following the hierarchical decision-making procedure proposed by Buchanan and Brock, in which the advance directive follows patient decision making and is followed by substituted judgment and best interest in subsequent steps [5].

Advance directive. The directive came into being with the primary objective of protecting individual autonomy. The document's title, its constituent parts, and the procedure by which it is prepared vary from state to state. It broadly consists of two parts and may document a person's wishes about life-sustaining treatment (living will), choice of a surrogate decision maker (durable power of attorney for health care), or both.

Mrs. Erickson has an advance directive in which she specified that she would like to receive all available medical interventions. However, there is no mention of whether the advance directive has been discussed, revisited, or modified since its formulation. Anticipating future medical situations and predicting what one's preference at that time might be are challenging. One study found that preferences about life-sustaining treatments changed in one-third of individuals over a two-year period [6]. Gready and colleagues have discussed that most individuals do not have insight and awareness into how their preferences change over time and may not modify the advance directives to reflect these changes [7].

One could assume that following what Mrs. Erickson stated in her advance directive would be the clearest way of respecting her autonomy. However, the age of the document and the disparities in her medical and functional status between the time her advance directive was drawn up and the present raise important questions about whether her best interests would indeed be served by uncritically following the document. Another factor that merits consideration is whether the directive covers the current clinical situation. For example, although directives of "do not resuscitate" and "do not intubate" are considered similar by clinicians, individual patients might not view them as the same. For this reason, it is appropriate to involve the family in the patient's care, even if the advance directive is unambiguous.

Smith and colleagues proposed a framework for striking a balance between previously expressed preferences and what might serve best interests at the present time. The factors they considered were how emergent the clinical situation is, the risk-benefit ratio of implementing versus withholding interventions, how well the advance directive fits the situation, the leeway provided by the patient to the surrogate for overriding the advance directive, and the team's assessment of how well the surrogate represents the patient's best interests [8]. Jonsen and colleagues recommended decision making based on four broad themes, namely, the medical indications, respect for patient autonomy, quality of life, and contextual factors, including but not limited to religious, financial, and legal considerations [9].

Based on the approach recommended by Smith and colleagues, we can state that our patient is faced with an important clinical problem, but one that is not an emergency and that affords the opportunity for careful deliberation. An advance directive is present but is an ambiguous fit with the current circumstances. We do not know of any leeway provided in the directive. The granddaughter, although identified as the next of kin, is young and has not engaged in end-of-life discussions with her ailing grandmother. Of note, whether and to what extent a surrogate decision maker can override what has been stated in the advance directive depend on state law.

Surrogate decision making. If a patient lacks decision-making capacity and the applicability of the directive is dubious, a surrogate decision maker's input may help in developing an accurate reflection of the patient's wishes. There are two approaches to surrogate decision making, namely "substituted judgment" and "best interest." In "substituted judgment," the surrogate "reports on" his or her knowledge

of the patient's preferences and values [10]. The "best interest" principle requires a surrogate to make a decision based on what he or she believes would best serve the patient's interests and well-being [5]. Of note, Braun and colleagues emphasize that the best interest principle should not presume that continuing life-sustaining treatment would necessarily serve a patient's best interest and encourage that a holistic approach to the patient's well-being be adopted [10].

If it is determined that Caitlin is making a decision, her feelings related to decision making should be discussed, for they can have an impact on whether the decision best serves the patient in question. Fritch and colleagues demonstrated that surrogate decision making is influenced by patient factors (input at the present time, past knowledge of values and best interest) and surrogate factors (the use of surrogate's own wishes as a guide, religious beliefs, the surrogate's own interests, family consensus, and feelings of obligation and guilt) [11]. The physician should be open to have an ongoing conversation with Caitlin throughout the course of Mrs. Erickson's treatment.

The medical community will be faced with an increasing number of such ethical dilemmas in the future, with the simultaneous advancement in technology to prolong life and the increase in the prevalence of individuals with dementias. As physicians, we will be serving our patients well by having discussions on advance directives early and revisiting them regularly. We also recommend that all physicians familiarize themselves with the federal and state statutes on decision making and involve consultation liaison psychiatry, the ethics team, or hospital's legal counsel, if needed, in complicated cases.

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THE CODE SAYS

The AMA *Code of Medical Ethics*' Opinions on End-of-Life Decision Making

Opinion 2.191 - Advance Care Planning

The process of advance care planning is widely recognized as a way to support patient self-determination, facilitate decision making, and promote better care at the end of life. Although often thought of primarily for terminally ill patients or those with chronic medical conditions, advance care planning is valuable for everyone, regardless of age or current health status. Planning in advance for decisions about care in the event of a life-threatening illness or injury gives individuals the opportunity to reflect on and express the values they want to have govern their care, to articulate the factors that are important to them for quality of life, and to make clear any preferences they have with respect to specific interventions. Importantly, these discussions also give individuals the opportunity to identify who they would want to make decisions for them should they not have decision-making capacity.

Proactively discussing with patients what they would or would not want if recovery from illness or injury is improbable also gives physicians opportunity to address patients' concerns and expectations and clarify misunderstandings individuals may have about specific medical conditions or interventions. Encouraging patients to share their views with their families or other intimates and record them in advance directives, and to name a surrogate decision maker, helps to ensure that patients' own values, goals, and preferences will inform care decisions even when they cannot speak for themselves.

Physicians should routinely engage their patients in advance care planning in keeping with the following guidelines:

- (1) Regularly encourage all patients, regardless of age or health status to:
 - (a) Think about their values and perspectives on quality of life and articulate what goals they would have for care if they faced a life-threatening illness or injury, including any preferences they may have about specific medical interventions (such as pain management, medically administered nutrition and hydration, mechanical ventilation, use of antibiotics, dialysis, or cardiopulmonary resuscitation);
 - (b) Identify someone they would want to have make decisions on their behalf if they did not have decision-making capacity;
 - (c) Make their views known to their designated surrogate and to (other) family members or intimates.

- (2) Be prepared to answer questions about advance care planning, to help patients formulate their views, and to help them articulate their preferences for care

(including their wishes regarding time-limited trials of interventions and surrogate decision maker). Physicians should also be prepared to refer patients to additional resources for further information and guidance if appropriate.

(3) Explain how advance directives, as written articulations of their preferences, are used as tools to help guide treatment decisions in collaboration with patients themselves when they have decision-making capacity, or with surrogates when they do not, and explain the surrogate's responsibilities in decision making. Involve the patient's surrogate in this conversation whenever possible.

(4) Incorporate notes from the advance care planning discussion in the medical record. Patient values, preferences for treatment, and designation of surrogate decision maker should be included in the notes to be used as guidance when the patient is unable to express his or her own decisions. If the patient has an advance directive document or written designation of proxy, include a copy (or note the existence of the directive) in the medical record and encourage the patient to give a copy to his or her surrogate and others to help ensure it will be available when needed.

(5) Periodically review with the patient his or her goals, preferences and chosen decision maker, which often change over time or with changes in health status. Update the patient's medical records accordingly when preferences have changed to ensure that these continue to reflect the individual's current wishes. If applicable, assist the patient with updating his or her advance directive or designation of proxy forms. Involve the patient's surrogate in these reviews whenever possible.

Issued June 2011 based on the report "[Advance Care Planning](#)," adopted November 2010.

Opinion 2.17 - Quality of Life

In the making of decisions for the treatment of seriously disabled newborns or of other persons who are severely disabled by injury or illness, the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life, as defined by the patient's interests and values, is a factor to be considered in determining what is best for the individual. It is permissible to consider quality of life when deciding about life-sustaining treatment in accordance with Opinions 2.20 Withholding or Withdrawing Life-Sustaining Medical Treatment, 2.215 Treatment Decisions for Seriously Ill Newborns, and 2.22 Do-Not-Resuscitate Orders.

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HEALTH LAW

Statutes to Combat Elder Abuse in Nursing Homes

Richard Weinmeyer, JD, MPhil

Introduction

Much of life is spent planning for the future. At a young age many of us are encouraged to save for college or that ever-nebulous “rainy day,” we plan out our careers and where we want to settle down, and, at some point along the way, we begin to plan for the golden years. The image often portrayed of growing old in the United States is one of comfort: a plush retirement with all the accoutrements of a peaceful conclusion to a life well lived. But for millions of elderly Americans, this is far from the reality they will experience. According to the most recent census data, 13 percent of people aged 65 and older live at or below the federal poverty level [1], in 2010 it was estimated that 8.3 million Americans over the age of 60 experienced food insecurity [2], and a quarter of elderly people struggle with mental health problems brought about by life limitations (e.g., a recent disability) and personal loss [3]. Perhaps nowhere are the elderly more vulnerable than in the very institutions where they go to receive medical care and social support: nursing homes.

Nursing homes are a common option for older people who require around-the-clock surveillance and on-site nursing care. As of 2011, roughly 1.4 million elderly Americans lived in nursing homes across the country [4], and, with the baby boomer generation filling the beds of these institutions, the numbers of those in assisted living facilities will rise markedly [5]. For a majority of nursing home residents, these care facilities provide safe and reliable surroundings [6], yet far too often nursing homes do not afford the protective atmosphere for which they are intended. Elder abuse is rampant in nursing homes throughout the United States [7], and, despite actions at the federal and state levels, personal stories of neglect, assault, and substandard care are too frequent to count, with many more incidents going unreported [8].

This article discusses the legal efforts made by the federal government to address the persistent problem of elder abuse in nursing facilities. Since the 1980s, two major legislative acts have sought to identify and correct abusive transgressions that have injured and even killed adults in the twilight years of their lives. Starting with the Nursing Home Reform Act in 1987, and followed by the Elder Justice Act of 2010, Congress has sought to close gaps in surveillance and corrective enforcement that have resulted in instances of elder abuse falling off the radar of law enforcement and regulators.

The Problem

The statistics about nursing home abuse are grim. A 2001 report authored by the Special Investigations Division of the U.S. House of Representatives' Committee on Government Reform disclosed that nearly one-third of nursing homes had been cited for violations of federal standards that had the potential to harm or had already harmed residents [7]. The report also found that approximately one out of ten nursing homes had violations that caused residents harm or serious injury or placed them at risk for death [7]. A survey of 2,000 nursing home residents provided equally disturbing data: 44 percent of interviewees stated that they had been abused and 95 percent said they had experienced or witnessed neglect [9]. Those responsible for the provision of care to elderly residents have admitted to such egregious behavior. In one survey, 17 percent of nursing assistants reported having pushed, grabbed, or shoved an elderly resident, and 51 percent reported yelling at a resident under their care [10]. The news media, too, bears stories of nursing home workers taunting patients [11], stealing from residents [12], and violently beating those who rely on their care [13].

Federal Regulations

Nursing Home Reform Act. The modern-day nursing home came into being with the passage of the Social Security Act of 1935 [14], which created federal government programs committed to reimburse facilities—formerly almshouses for the poor and elderly—to care for aging Americans [15]. In subsequent years, concerns about quality, a lack of facilities, and a growing market for private nursing homes spurred some action by Congress in the public nursing home arena, but it was the passage of Medicaid and Medicare in the 1960s that made more public funds available for nursing care and established hospital-like standards that nursing homes had to meet in order to receive public dollars [16]. But these standards focused on the facilities, rather than on the quality of care provided [15].

In 1987, following a wave of publicity that highlighted the poor standard of care given to nursing home residents, Congress enacted the Omnibus Budget Reconciliation Act (OBRA) to address the concerns about deficient care [17]. Known as the Nursing Home Reform Act, OBRA created a regulatory scheme to actively monitor and enforce quality of care standards for nursing facilities nationwide [18]. The act proclaims that a nursing home “must care for its residents in such a manner and in such an environment as will promote maintenance or enhancement of quality of life for each resident” and that it must “provide services to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident” [17].

These regulations also set forth a bill of rights for residents of nursing homes that participate in Medicaid and Medicare [19, 20]. It includes, but is not limited to: the right to receive reasonable accommodation of needs; the right to freedom from abuse, mistreatment, and neglect; the right to privacy; the right to be treated with dignity; the right to voice grievances without discrimination or reprisal [21]. Furthermore, nursing homes are required to meet specific quality-of-care standards,

including the prevention of pressure sores, proper treatment and assistance with vision and hearing, treatment and care for urinary incontinence, and so on [22].

CMS determines whether a nursing home is able to abide by these rights and standards through a series of nursing care surveys conducted by contracting agencies in each state [18]. Each survey is intended to measure different levels and dimensions of quality and to certify that the home is continually meeting federal requirements [18]. Deficient institutions face a variety of sanctions, such as civil monetary penalties, termination of participation in federal and state funding programs, or closure of the facility, depending on the violation.

Elder Justice Act. The most recent federal action taken to address the continuing problem of elder abuse in nursing facilities is the Elder Justice Act (EJA) [23], which was enacted as part of the Patient Protection and Affordable Care Act of 2010 (ACA) [24]. This provision of the ACA is considered to be the most comprehensive bill ever passed to combat elder abuse, exploitation, and neglect [25]. Based on the research conducted by the Government Accountability Office demonstrating existing gaps in federal and state safeguards to protect the elderly from harm, Congress set forth the EJA to expand efforts through both the Department of Justice and the Department of Health and Human Services in unearthing and stopping abuse [26].

The EJA adds to the surveillance and enforcement activities to stop elder abuse in nursing homes and more broadly in long-term care facilities in a number of ways. First, the act authorized additional funds for state ombudsman programs—those offices and officers charged with addressing elder care concerns in every state—to carry out investigations into abuse accusations and to establish training programs for organizations and state agencies working with them [27]. Funds have also been authorized for the establishment of a national institute to assist federal and state surveyors who conduct investigations of allegations of abuse, neglect, and exploitation in Medicaid- and Medicare-certified nursing homes [28].

The second pertinent piece of the act is the availability of funds that long-term care facilities and community-based organizations can use to attract and train people interested in providing direct care to the elderly and to provide those workers with continuous training and certification in the field [29]. Finally, the EJA has established strict mandatory reporting requirements for those who suspect that crimes against elderly residents in long-term care are being perpetrated [28]. Every employee or contractor associated with a long-term care facility is required to report any reasonable suspicion of elder abuse to the Secretary of Health and Human Services as well as to law enforcement agencies [28]. Failure to report such suspicions can result in civil monetary penalties of up to \$300,000 and the possible exclusion of nonreporting individuals from federal health care program reimbursement [28].

Conclusion

Eliminating elder abuse in nursing homes continues to be an elusive goal. Given the evidence that far too many Americans fall victim to unscrupulous actions of nursing home employees and operators, the federal government has steadily moved forward in its oversight of these facilities, particularly with the passage and implementation of such legislation as the Nursing Home Reform Act and the Elder Justice Act. Just as OBRA brought about significant reform to a once poorly understood and fairly unregulated area of elder care, it is hoped that the EJA will hold the same promise with its multifaceted approach to curbing elder abuse across the country.

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POLICY FORUM

The Exclusion of Older People from Participation in Cardiovascular Trials

Jerry H. Gurwitz, MD

According to the US Food and Drug Administration (FDA), “Patients included in clinical studies should reflect the population that will receive the drug when it is marketed.... There is no good basis for the exclusion of patients [from participation in clinical trials] on the basis of advanced age alone.... If a drug will be used in conditions where specific concomitant diseases are likely to be present, an attempt should be made to include in the treatment population patients with other diseases” [1]. These principles were highlighted by the FDA in a 1989 guideline for the study of drugs likely to be used in the elderly. Unfortunately, that guideline has largely been a failure, and the profound lack of evidence to guide clinical decision making in the care of older adults presents mounting challenges for US physicians, patients, and families as the nearly 80 million baby boomers age into their geriatric years.

In 1992, Nanette Wenger wrote that “the profile of cardiovascular illness in the United States has shifted to encompass predominantly elderly populations...yet it is precisely in this population that the traditional exclusion, or at best underrepresentation, of elderly persons in clinical trials has generated an information void” [2]. A pattern of exclusion of elderly persons from participation in cardiovascular clinical trials has been apparent since the first large randomized clinical trials were conducted in the 1960s [3-5]. For example, the vast majority of patients with heart failure are older than 65 years of age [6], yet Masoudi and colleagues have described a “voltage drop” in eligibility of older subjects in studies of treatment for heart failure [7]. More than 40 percent of Medicare beneficiaries who survive hospitalization for heart failure would have been deemed ineligible for participation in the landmark studies of left ventricular dysfunction trial and the Metoprolol controlled release/extended release intervention trial in congestive heart failure merely on the basis of age [7].

More recently, Cherubini and colleagues examined data from ongoing heart failure studies in the World Health Organization Clinical Trials Registry.[8] These investigators assessed the proportion of trials that excluded patients according to an arbitrary upper age limit or by criteria that might indirectly limit the participation of older persons. Of 251 trials, more than a quarter excluded patients based on an arbitrary age limit. Overall 109 trials (43 percent) had one or more poorly justified exclusion criteria that could limit the participation of older study subjects. Poorly justified criteria included comorbidity described in a non-specific manner, use of medications that would not impact the study protocol, and visual and hearing impairment that would not lead to safety concerns.

The resulting paucity of relevant clinical evidence worsens a quandary faced by physicians in making clinical decisions in providing care to older patients. Physicians struggle with the dilemma, on the one hand, of using treatments that may not be beneficial and that could cause harm to a patient or, on the other, denying effective treatments to patients at high risk for dying who could benefit from more aggressive management [9]. The ethical principle of beneficence requires that a clinician follow two general rules. The first is to “do no harm” (nonmaleficence), and the second is to “maximize possible benefits and minimize possible harms” [10]. According to Pantilat, “Physicians should not provide ineffective treatments to patients, as these offer risk with no possibility of benefit and thus have a chance of harming patients. In addition, physicians must not do anything that would purposely harm patients without the action being balanced by proportional benefit” [11].

Physicians also have an ethical responsibility to use resources wisely. Tilburt and Cassel have called this “parsimonious medicine”—the delivery of care that fits the needs and circumstances of patients and avoids wasteful care that does not benefit them [12]. Parsimonious medicine should not be considered rationing, which is the “explicit or implicit withholding and allocation of beneficial resources from some patients for the sake of others” [13]. Physicians must be stewards of health care resources, and they have an ethical obligation to employ them wisely [14]. High-quality evidence is required to fulfill this important responsibility.

Clearly, a multifaceted approach is required to improve the evidence base to guide the care of older patients with cardiovascular disease. Some possible initial steps include [15]:

- Eliminating arbitrary age-based exclusions in cardiovascular clinical trials;
- Requiring strong justification for exclusion criteria, including those relating to comorbidity, medication use, and functional and cognitive impairment, that affect the inclusion of older people;
- Encouraging clinical trials specific to older individuals through targeted federal funding;
- Publicizing trends in the inclusion of elderly patients in cardiovascular clinical trials to assess progress in improving the generalizability of research findings to this high-risk population; and
- Requiring direct evidence of benefit in making national coverage determinations regarding services for Medicare beneficiaries, which would serve as a powerful incentive to enhance the participation of older persons in clinical trials [16].

There will always be uncertainties regarding the risks and benefits of a particular therapy or intervention in an individual patient. Yet as Lowenthal and colleagues have written [17], it is essential to gather reliable evidence through RCTs “to inform the care of future patients, the fairness of present and future access [to effective therapies], and the value of stewardship of limited resources” [18].

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POLICY FORUM

Medicare and Means-Based Fees

Richard G. Stefanacci, DO, MBA, MGH

Means-based fees have been a part of the practice of medicine since doctors began treating patients. Well before Medicare and Medicaid were introduced in 1965, physicians commonly charged a lower rate for patients with lower means and allowed patients to adjust their payments based on their ability to pay. When Medicare came along, it was financed through payroll taxes, tied, of course, to employees' incomes. Most, however, did not view this income-based payroll tax as means-based until many years later, when income adjustments were made directly to Medicare premiums, first for the Part B program and most recently the Part D program [1].

Several Forms of Means-Based Adjustment

Although adjustment to premiums—the amount paid for insurance coverage, regardless of use of services—is often considered the basic form of means-based pricing (premium adjustments are made based on one's income and assets), there are in fact two other ways in which means are taken into account in determining the price a particular person pays for health care: taxation and out-of-pocket costs.

The principal purpose of means-based pricing is to subsidize beneficiaries with lower incomes. This concept was introduced at the outset of Medicare in 1965. A major component of Medicare funding comes from individual income-based payroll taxes—a flat payroll tax (at a rate of 2.9 percent, shared equally between employers and employees) [2, 3], though some elements of the program are funded by general revenue and by premiums paid by enrollees [4].

Medicare parts B and D premium adjustments. Within the last decade, a premium adjustment was added to Medicare and has been expanded in recent years. This adjustment was first applied to the Medicare Part B premiums and was added to the Medicare Part D program in 2011 [1]. The premiums for Medicare Part B (which covers physician services, outpatient care, and medical equipment) and Part D (which covers prescription drugs) are higher for wealthier retirees [5]. Today, roughly 5 percent of retirees pay higher Part B premiums based on their incomes [1]; due to the Affordable Care Act (ACA), this share will rise to around 14 percent over the next decade because the law will end the practice of adjusting income thresholds for inflation [6]. Under the Part D prescription drug program, about 3 percent of beneficiaries currently pay income-adjusted premiums [7]; this number also will rise under the ACA to about 9 percent. This represents a threefold increase in the number of Medicare beneficiaries who will have higher premiums due to their income levels.

Health insurance marketplaces. With the introduction of the health insurance marketplaces (HIMs) in October 2013, means-based adjustments are occurring in both the premium subsidies and penalties. (The tax penalties go into effect in 2014; if a citizen or documented immigrant is uninsured for more than 3 months in 2014, he or she will incur the tax penalty, which will be applied to his or her 2014 income tax return, except in cases of financial hardship, membership in certain religious groups or Native American tribes, or incarceration [8, 9].) The amount of the penalty is based on the person's taxable income.

Drug Pricing for Dually Eligible Beneficiaries

As mentioned previously, means-based price adjustments are also applied to patient out-of-pocket expenses, specifically in the Medicare Part D prescription drug plan. The lowest-income people—those with Medicare who also are covered by Medicaid and, hence, called “dual eligibles”—pay only a few dollars for their prescription medications: \$1.15 per generic prescription and \$3.50 for brand-name products [10]. Dually eligible patients have no incentive to opt for cheaper generic drugs because the price difference is so small. Conversely, higher-income Medicare beneficiaries might be charged as much as several hundred dollars for the same brand-name medication, nudging them to make the less costly choice.

MedPAC has explained that Part D plans are limited in their ability to modify drug co-payments for low-income subsidy (LIS) enrollees, which is why brand-name drug co-pays for this group of enrollees do not differ significantly from generic drug co-pays [11, 12]. MedPAC has recommended that Congress modify the Part D low-income subsidy co-payments for Medicare beneficiaries with incomes at or below 135 percent of the federal poverty level to encourage the use of generic drugs when available in selected therapeutic classes.

Potential Problems in Means-Based Price Adjustments

The principle behind means-based price adjustments is collecting more funds from those with greater means to subsidize support for those with lower incomes. Chief among the challenges to this principle is disagreement about fairness or equity. Specifically, policymakers must grapple with determining the levels at which society will agree that one group deserves to receive support and another to contribute to the support of the first group. Consider for example, the rich tradition of social solidarity and workers' organizations in European countries. In my opinion, it is this heritage of solidarity, along with fairly homogenous national populations, that has led to health policies in those countries that reflect a collectivist spirit. In the United States, there are myriad social cleavages across cultural, economic, and political lines, so that consensus on equity and fairness of health policy is extremely difficult to reach. Suffice to say, this is a difficult political discussion and one that is outside the scope of this discussion and of the typical focus of most physicians. What is most pressing for physicians is pricing that ensures appropriate health care resource utilization, neither underuse nor overuse. This is the area where physicians should be most actively involved.

If the application of means testing sets the bar for assistance or subsidy too high, poor patients might underutilize needed medical services. The opposite is true as well. When means testing sets the level for assistance too low, overuse can contribute to waste, or worse, to unnecessary patient interventions that carry risk and can be harmful. By voicing their opinions to regulators and legislators, physicians can play a role in assuring the proper balance in means testing so that utilization levels are most efficient, effective and equitable.

Optimal Means-Based Adjustments

To apply means-based adjustments optimally, society must identify services that are considered essential—meaning that it is not acceptable for people to forgo or have less of them due to inability to pay—and why. In the United States, this group of services might be adapted from the services which the ACA requires a health plan to provide in order to participate in the health care exchange marketplace. Such services could include vaccinations, which are often cited as one of the most cost-reducing health care services to a society. At the other end of the spectrum, one might argue that medications to promote hair growth do not have sufficient value to society to justify public payment for them. Consider a tougher example: treating a younger patient with advanced cancer may be deemed to have higher societal value than the same treatment for an older person, in which case the decision might be made to subsidize more of the cost of treatment for the younger patient.

Although there may be some controversy even about the first example I cited, great debate is certain to surround all of the areas in the middle because citizens in a diverse society have varying priorities. The bottom line is that policymakers, with input from the medical profession about which services are most needed, must devote the necessary attention to determining the means-based pricing that will lead to optimal use of services, that which is neither harmful nor wasteful.

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MEDICINE AND SOCIETY

Who's Responsible for Granny?

Carol Levine

On July 30, 1965, when President Lyndon B. Johnson signed the bill that created Medicare, he outlined an ethical vision for the nation's obligations to its older citizens. "No longer will older Americans be denied the healing miracle of modern medicine," he said. "No longer will illness crush and destroy the savings that they have carefully put away over a lifetime so that they might enjoy dignity in their later years. No longer will young families see their own incomes, and their own hopes, eaten away simply because they are carrying out their deep moral obligations to their parents, and their uncles, and their aunts" [1].

That was then. Remember that, in 1965, 19 million Americans 65 years and older were eligible for Medicare [2]. Life expectancy for men was only 66.8 years and, for women, 73.7 years [3].

This is now. Almost 44 million people are 65 and older. [4]. Women who reach the age of 65 now have a life expectancy of 20.4 more years; for men, it's 17.8 more [5]. That's a boon to the healthy and well-off, but a challenge for those who are sick and poor.

And we are just at the beginning of this huge demographic shift. The US Census Bureau estimates that by 2030 nearly 20 percent of the population—72 million people—will be 65 and older. By 2034 all the baby boomers—people born between 1946 and 1964—will be 74 years old or older. By 2040 there will be almost 80 million people over 65, twice as many as there were in 2011. And the number of "oldest old"—people 85 or older—is projected to increase from 5.7 million in 2011 to 14.1 million in 2040 [6].

Other major changes have occurred since the 1960s. Women, the traditional caregivers for older people, have entered the workforce in record numbers. Families are smaller [7, 8], which means fewer people available to provide and pay for care. Chronic illnesses have replaced acute illness and trauma as the leading indicators of morbidity and mortality [9]. Hospital stays are short and mostly managed by hospitalists, not family physicians. Technology of all kinds has changed medical practice and has made private homes extensions of hospital care. Hospice and palliative care, unknown in America in earlier times, are widely available, though still underutilized. And, as everyone knows, the costs of medical care have increased rapidly. It is hard to think of the medical enterprise today without calculating its

financial winners and losers. Among the losers is long-term care, which is low-tech and low-reimbursement.

What do these far-reaching demographic, cultural, and economic shifts mean for older people, families, and society? President Johnson's description of older people as deserving the nation's gratitude and support may seem idealistic, even naïve, today. This was after all the 1960s, when hope and optimism were widespread and government programs to alleviate poverty and end discrimination had public support, even though it took years to get Medicare through Congress. Today most descriptions of the aging population use ominous terms—the “silver tsunami” or an “elderquake” [10, 11]. Older people are sometimes seen as an insatiable drain on limited resources, which in the richest country in the world are limited mainly by public willingness to pay. Despite the protestations that elderly people are consuming resources unfairly, a recent review of the health care system found that demand for services among the aging population is not the primary reason for the increase in health care costs since 1980. Since 2000, higher prices (especially for hospital stays, professional services, and administrative costs) accounted for 91 percent of the cost increases [12].

The past of course should not be seen through a soft-focus lens. Racial discrimination, sexism, and physician paternalism that would today be considered unacceptable were common in medical practice. Still, it is appropriate to ask: Should compassion and inclusiveness be abandoned? Has our culture become so enraptured by youth and wealth that we see their opposites only as undesirable burdens?

Caring for an Older Population: Still Largely a Family Responsibility

One factor has remained constant over the years: most family members continue to feel a moral obligation to care for their parents, aunts, uncles, grandparents, siblings, friends, and others to whom they have a deep commitment. Medicare was enacted after a long political struggle partly on the basis that it would help not only older people but also their families by removing the financial burden of medical care. The reality, however, is that individuals and families still suffer under the financial weight of medical bills and the costs of unreimbursed care. While Medicare pays most of the bills for hospital stays and physician visits, as well as limited home care and rehabilitation services, it does not pay for long-term care in a nursing home or long-term services and supports in the community. Medicaid pays for long-term care, which is frequently what older people need most, but there are stringent income and asset eligibility criteria. This is a “safety net,” to be sure, but only for some, and it comes with strings attached.

Most older people do not live in nursing homes or in assisted living facilities but in their own or their family members' homes, where overwhelmingly they want to be [13]. Occupancy of nursing homes has declined in recent years. About 1.4 million people—around 4 percent of the over-65 population—lived in the nation's 15,465 nursing homes in 2011. Not many new nursing homes are being built and many existing facilities are shifting toward smaller, homelike settings [14]. And although

there was a boom in assisted living facilities in the 1990s [15], growth has slowed because the volatile housing market has made it difficult for some older people to sell their homes to pay the entry fees [16].

Nursing homes have increasingly focused on short-term rehabilitation services, paid for by Medicare and private insurance, rather than long-stay residents, paid for largely by Medicaid [17]. And states have tried to replace expensive nursing home care with home- and community-based services [14], resulting in a patchwork of programs and services, many with long waiting lists. Coordinating these services is a major challenge, and one that is often left to family caregivers.

Unpaid family caregivers provide an estimated 80 to 90 percent of long-term care outside of nursing homes or medical facilities [18]. And they do so while they maintain full- or part-time jobs; care for other members of their families; and pay out-of-pocket for the many deductibles, copays, and items that insurance does not cover. Family caregivers provide an estimated \$375 billion worth of care each year, but, because it is unpaid care, it is largely ignored in economic calculations of the health care enterprise [19].

Just as significantly, family caregivers have become unpaid and untrained lay nurses, routinely providing complex care such as medication management, infusions, and injections; wound care; monitoring of medical equipment; and other tasks. An AARP Public Policy Institute/United Hospital Fund national survey of family caregivers found that nearly half (46 percent) were performing one or more of these tasks, in addition to the more traditional help with activities of daily living (ADLs), such as bathing and dressing, and instrumental activities of daily living (IADLs), such as shopping and transportation. And fully 61 percent said that they learned on their own how to do these demanding tasks. Most do not have paid help from nurses or home health aides. They are, as the title of the report suggests, “home alone” [20].

What Kind of Care Do Older People Need?

The “healing miracle of modern medicine,” cited in President Johnson’s statement, was even then an aspiration rather than a reality. Certainly there have been enormous advances in diagnosis and treatment, especially of infectious diseases and trauma, which at least in part have contributed to increased longevity. Public health measures such as immunization have made survival to adulthood more common. But most people who reach advanced ages suffer from progressive chronic illnesses and frailty, accompanied by loss of physical and cognitive function. One-third of the people who live past the age of 85 will have Alzheimer disease [21]. These conditions are not amenable to technological wizardry.

Joanne Lynn, a geriatrician and palliative care advocate, assesses the current situation in this way:

Although the elderly person would usually prefer comfort, function, meaningfulness, and living at home, the current “care system”

provides disjointed specialty services, ignores the challenges of living with disabilities, tolerates routine errors in medications and transitions, disdains individual preferences, and provides little support for paid or volunteer caregivers [22].

Among her recommended solutions are recognizing that “frail elderly people have different priorities and needs than they had earlier in life, and their care system must reflect these priorities” [22]. This is simply a restatement of the principle of respect for patient autonomy, which should underlie all health care decision making. Some people want “everything” to be done, while others opt, if given full information, for pain and symptom control and a focus on quality of life—in other words, palliative care. But in the push (sometimes from families, sometimes from professionals themselves) to do something, the chances of meaningful benefit and serious risks are put aside. What, for example, is the benefit to an 85-year-old man with advanced dementia of an aggressive dialysis regimen [23]?

Lynn emphasizes, as do other commentators, that “the service delivery system should encompass health care and LTSS [long-term services and supports] as equal partners” [24]. This was a key recommendation of the federal Long-Term Care Commission [25]. But it is hard to change longstanding beliefs and practices to create a seamless continuum of care, so often glibly described but infrequently instituted.

Conflicting American Values

American society is a mass of contradictions; when a natural or manmade disaster occurs, at home or abroad, Americans give generously in time and money to help those who have been affected. Volunteers support many important community services. Yet proposals to spend taxpayer money on services to help people who are poor, hungry, homeless, or just frail and elderly are resisted vigorously. Americans value self-sufficiency and mainly see the meeting of needs as a personal responsibility, not a collective one.

Despite a frequently negative view of older people, let any politician or commentator suggest that doctors should discuss end-of-life choices with their elderly patients, and there will be an outcry against so-called “death panels” bent on “killing Granny” [26-28]. Yet proposals for more services for Granny and her family caregivers are voted down because “Granny should have saved her pennies for long-term care” or “Taking care of Granny is the family’s responsibility.”

Ethical Responsibilities

If we are a truly democratic and humane society, we are all responsible for all Grannies—mine, yours, and everyone else’s. Individuals should be given affordable options to plan and save for their future care needs without becoming impoverished; families should be trained and supported in their willingness to provide care but not coerced to take on that role; professionals should recognize the individuality and preferences of their older patients and not be pressured to base decisions on the

financial interests of their institutions. Finally, responsibility for shouldering the cost of care should be shared between private and public sources.

From an ethical perspective, family caregivers who accept these responsibilities, most of whom do so without any semblance of informed consent, should not be expected by health care professionals and policymakers to manage on their own. Health care professionals have responsibilities to train and support family caregivers and to recognize both their strengths and limitations. They also have obligations to their colleagues during transitions—for example, from the hospital to home care—to provide appropriate information about the patient and family caregiver to the next set of clinicians.

There are also social responsibilities to ensure appropriate housing, transportation, nutrition, places for social activities, and all the other aspects that make a community “friendly” to children, the elderly, people with disabilities, and so on.

The Affordable Care Act, with all its problems and limitations, took up the fundamental problem of access to health care. But we need to do more. Our health care and long-term care systems need to be integrated and updated in a way that both recognizes the vision of Medicare at its inception and the real world we live in today. This is as much an ethical imperative as the passage of Medicare was in 1965.

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MEDICINE AND SOCIETY

Baby Boomers' Expectations of Health and Medicine

Eva Kahana, PhD, and Boaz Kahana, PhD

In the early 2010s, the first cadre of baby boomers, born after World War II, turned 65, making them officially senior citizens, and many more are joining their ranks every day. It is generally acknowledged that the entry of the baby boomers into the ranks of elderly consumers of health care is likely to create major challenges. As large numbers of baby boomers cross into old age, there will be greater demands for chronic health care and for meeting the special needs posed by the “graying of disability”—people with disabilities living longer than they did in centuries past. The coming changes in health care needs are generally conceptualized in terms of increasing demand and need for responsiveness by overburdened health care professionals [1].

Involvement and Assertiveness

But acknowledging only the growing demand for care and the inadequacy of our current system to meet it ignores the advantages of having a new breed of elderly patients. Baby boomers are different from the generations that preceded them; they are more savvy, assertive, health-conscious, and engaged in their care [2, 3]. Even recently, the literature of medical sociology has portrayed older adults as reluctant to speak up to their doctors and passive in communicating about their health care [4, 5]. Consequently, the focus of patient-centered medicine has been on training physicians to draw out shy and reticent elderly patients and provide them with more thorough information about their health care options [6].

Our recent research has involved interventions to encourage older adults to be more proactive in communicating with their clinicians [7]. As part of a randomized controlled trial (RCT), we are evaluating the efficacy of a patient communication intervention—“Speak Up”—compared to a civic engagement-oriented attention control group—“Connect.” During the four-year period of this study, we have noticed a marked increase in patient preparedness and initiatives and an increasingly active group process in which study participants offer advice to one another about speaking up to their primary care physicians and requesting test results and other data about their health status and care needs [7]. Indeed, longitudinal studies of successful aging [8] have revealed important changes in health care consumers' expectations, involvement in their own health care, and competence in navigating the health care system. Baby boomers are among the most avid consumers of health information and approach their health care providers with far greater initiative and than did older adults of yesteryear [9]. Baby boomers value and pursue social

engagement and healthy lifestyle behaviors and have high expectations for wellness and independence in late life [10].

Members of the baby boomer generation are also playing a growing role in long-term care of the oldest old [11]. Growing numbers of them are caregivers to their parents. People are living longer and have smaller families, demographic trends that have created new demands on their baby boomer children [12]. As caregivers who are themselves dealing with the chronic illnesses of later life, boomers can serve as more understanding health care advocates.

There are important implications of this sea change in patient involvement in health care among baby boomers reaching old age. Physicians must now be prepared to interact with older patients in the same way they interact with younger patients, engaging in a more egalitarian dialogue and involving patients more earnestly in decision making.

Independence

Older patients of the present and future expect to live more active lives and seek to remain socially engaged, even as they manage chronic illnesses or rehabilitation from disabling health conditions. This generation of self-determining patients is likely to question established principles of medical care, demanding greater attention to their own definitions of health-related quality of life [13]. This is a fundamental move away from the traditional positivistic medical outcome criteria in the direction of “the new subjective medicine” that recognizes and seeks to enhance subjective criteria for health outcomes [14]. Recognition by physicians of the importance of patient values, expectations, and subjective appraisals of health and quality of life can facilitate better communication and shared decision making.

It has been recognized that ageism often limits the choices of older adults regarding long-term care [15]. While there have been meaningful efforts to offer *young* patients long-term care options that allow maximum control of care received and choice of caregivers, options for *elderly* patients with disabilities have been far more restrictive. If the new elderly place a higher premium on self-reliance, they may be eager to consider long-term residential options that facilitate independence. Our study of successful aging reveals that, among older adults who retire to Sunbelt retirement communities, those who enter continuing care living facilities maintain independence for a long time, even with multiple comorbidities [16]. Options of this kind, which promote choice and do not necessitate moving to be near other family members, may be particularly popular with baby boomers.

Technology

The elderly patients of today use the technological resources of the Internet [17]. Our smartphone-toting baby boomers carry great resources along with great expectations, literally at their fingertips. Mobile phones can enable the majority of older adults to access diverse health interventions, ranging from education to health monitoring, and health promotion. This can facilitate patients’ sense of agency and self-efficacy

about improving their own health [18]. Technology can play an important role in making it possible for older adults to “age in place,” and online interventions have facilitated patient empowerment [19]. To the extent that patients can retain control, they will happily incorporate technology into their self-care and self-monitoring routines. Accordingly, baby boomers and older adults have shown similar levels of acceptance of monitoring technology as long as doing so facilitates independent living [20]. But clinicians must be sensitive to the wishes of baby boomers and older adults who may not desire externally imposed health and safety monitoring that they view as an invasion of their privacy [21]. For example, our research revealed that very few independently living older adults in the “wired” community of Celebration, Florida, opted to have telemonitoring of their blood glucose or blood pressure by the local health center [22].

As we consider the implications of this changing health care landscape for physicians, we have to acknowledge that doctors will continue to play a central role in that brave new world. Studies continue to confirm that patients place greatest trust in information they obtain from their physicians, but more and more older patients look for information online before they consult their physicians [23]. Consequently, physicians must embrace technology in meaningful, rather than pro forma, interactions with their older patients. For example, the reluctance of doctors to exchange e-mails with patients deserves a second look. There is evidence that physicians who regularly use e-mail in communicating with colleagues overwhelmingly refrain from doing so with patients [24]. Research indicates that interventions encouraging doctor-patient e-mail communication yielded positive results for both groups [25]. As baby boomers seek efficient and timely communication with physicians to help in coping with chronic illnesses, access to e-mail communication can yield clear benefits.

Despite the possible challenges posed by baby boomers’ expectations for better quality of life in their older years, the health-promoting lifestyles they have embraced and popularized will pay dividends in improved health outcomes and reduced burdens for the physicians treating them. Indeed, it has been argued that interest in active lifestyles and healthy diets by baby boomers is fueling the wellness revolution in our society [2]. It is well recognized that health-promoting lifestyles can delay the onset of chronic illnesses and diminish dependence on health care services [26]. And the future may also hold as-yet unheralded medical advances that will benefit these patients as well as their doctors.

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HISTORY OF MEDICINE

Geriatric Medicine: History of a Young Specialty

Mary Ann Forciea, MD

The fascination of Medicine lies in its basic qualities—its wide social and humanitarian aspects, its progressive nature and its variety. Of all branches of Medicine, that of treatment of the chronic elderly sick has received, so far, less attention than others and consequently offers the widest scope for pioneer work and research.

—Marjory W. Warren, 1948 [1]

While devoted to the care of elderly patients, the specialty of geriatric medicine is itself young. The field was named, professional societies formed, and specialized training programs certified all during the twentieth century. Competencies required for geriatrics in medical education were developed early in the twenty-first century. Geriatric medicine joins the group of medical specialties that are defined by stages of human development (such as pediatrics, neonatology, and adolescent medicine), rather than by organ system (cardiology, neurology, and gastroenterology).

Although the formal organization of geriatric medicine happened recently, interest in aging and the realization that certain diseases cluster in older patients has existed since antiquity [2]. In Egyptian hieroglyphs, images for old age are associated with the kyphosis of osteoporosis [3]. Aristotle and Galen both examined the connection between metabolism (heat generation) and aging. Galen, in fact, proposed that changes associated with aging could be delayed by attention to diet and exercise [3]. Still, the numbers of people who achieved old age in ancient times was very small; the median length of life in ancient Egypt was less than 30 years.

During the late Middle Ages and early Renaissance, knowledge of physiology began to increase. Physical scientists like Francis Bacon developed an idea that aging was produced by unequal repair rates in different organs. Scientists began to look at aging and disease processes like the “hardening” of fibers and arteries in older persons [3]. The concept that aging might increase vulnerability to specific diseases began to be explored. By 1793, Benjamin Rush declared in the new United States that “few people die of old age” [4]. Investigation into the aging process led to the field of gerontology, the science of the study of aging.

Equally important to early philosophers and scientists when thinking about aging phenomenon was whether these processes could be reversed. Rejuvenation of organs or whole persons was widely desired, and a variety of techniques or substances was proposed. Bathing in special waters (the “Fountain of Life”) or in bodily fluids

(mother's milk, the blood of virgins) was believed to restore youthful vigor [2]. The ingestion of numerous compounds was encouraged (herbs, alcohol, animal testicles), and sexual encounters (especially with virgins) were all recommended. Even today, companies offer an array of products aimed at reversing aging: a recent Google search for "rejuvenation products" yielded more than 6 million entries. While science and medicine have improved the numbers of people living to older ages, and have contributed to increased function in late life, the restoration of youthful vigor in late life remains elusive.

In 1909, Ignatz Nascher proposed the term "geriatrics" for care of the elderly, explaining,

Geriatrics, from *geras*, old age, and *iatrikos*, relating to the physician, is a term I would suggest as an addition to our vocabulary, to cover the same field in old age that is covered by the term pediatrics in childhood, to emphasize the necessity of considering senility and its disease apart from maturity and to assign it a separate place in medicine [5].

Until Nascher's time, older adults were not treated differently or in different ways than other adult patients. But social forces came into play in the period during World War I and World War II that both necessitated and facilitated long-term care for the elderly: The number of elderly people began to increase due to improvements in economic conditions and medicine. Large numbers of young wounded soldiers required long periods of care, and they and their families were able to advocate for better facilities and standards. An increase in the professionalism of medicine, nursing, and social work produced health care professionals with training in clinical care and research into the specific problems of their patients.

Great Britain led in the development of clinical care for the elderly in the early twentieth century. During the period between the World Wars, Britain reorganized many of its "chronic" hospitals. Acute hospital units and home services were added, and some chronic hospitals focused on medical long-term care, rehabilitation, or psychiatric care. In 1935, Marjory Warren, a young physician, was given the responsibility of caring for patients at a "chronic sick" hospital. She assessed all the patients and organized the patients and wards into five categories: "chronic up-patients (ambulatory); chronic continent bed-bound patients; chronic incontinent bed-bound patients; senile, quietly restless (not noisy or annoying) patients; and senile dementia (noisy and/or annoying) patients" [6].

She published a series of articles advocating and describing techniques for the assessment of patients that would allow them to be placed in the right type of long-term care facilities [7, 8]. Decades later, Warren's call for "assessment" of older patients was echoed in the United States by T. Franklin Williams and colleagues [9]. Warren ultimately recommended specialized training for medical students in the care of the elderly chronically ill, as well as in locating long-term care hospitals near

teaching hospitals to facilitate training and research into methods of care. She stated when speaking of her older patients, “These worthy people, whose lives have been every whit as useful as we would like to believe our own, are ill housed with younger folk who are irritated by them, and in turn annoy them” [10].

The principles developed by Warren and her colleagues were championed by the British Geriatric Society, which was established in 1947, and incorporated into the National Health Service when it was established in 1948 [11]. Geriatricians in the new National Health Service led in the creation of networks of care for older patients.

In the United States, roughly similar societal pressures (increasing numbers of the elderly and increasing demand on long-term care accommodations for the chronically ill elderly) contributed to new paradigms of care. Public policy during the twentieth century began to accommodate the economics of older patients. The Social Security Act of 1935 introduced guaranteed federal income assistance for the elderly and disabled. In 1965 President Lyndon Johnson signed the legislation establishing Medicare, a health insurance program for the elderly, and Medicaid, a program of social support for the poor of all ages. By the mid-twentieth century, then, it had become economically feasible for older people to receive treatment in hospitals, primary care settings, and long-term care settings. As advances in medical science and surgery have allowed people to live longer with multiple chronic conditions, the percentage of older patients cared for by almost all specialties has risen.

Physicians interested in focusing their practices on the elderly came from a variety of care settings. Older patients living in long-term care facilities offered an early, obvious patient population for specialty care. Physicians practicing in home care also contributed to the development of geriatrics. Martin Cherkasky described the clinical and financial benefits of providing in-home care to older chronically ill patients in New York City in 1949 [12]. The Veterans’ Administration began to sponsor innovation in the care of the elderly through its Geriatric Research and Education Clinical Centers (GRECC) in 1976 [13]. Leslie Libow published an article on the “Teaching Nursing Home” in 1984 [14] and developed the first fellowship training experience in geriatric medicine in the United States. Our practice at the Philadelphia VA Medical Center published the first description of a geriatric model system originating in a primary care practice [15]. The Hartford foundation sponsored the early development of acute inpatient care units for older patients: acute care of elders (ACE) units, many of which persist today [16].

Training in geriatric medicine sprouted from all these clinical settings. The National Institute on Aging, founded in 1974, sponsored training at many levels. The American Board of Internal Medicine offered a certification of added qualification in geriatrics in 1988. Professional associations like the American Geriatrics Society (1942), the American Medical Directors Association (1978), and the American Academy of Home Care Physicians (1988), among others, have been strong

advocates for standards of training, for accreditation of facilities, and for legislation to improve the care of the elderly. These societies remain involved in establishing competency standards for practice for trainees at all levels.

Coming increases in the numbers of frail older patients will strain the small supply of geriatricians as well as the primary care physicians of the future. Innovation in reimbursement for team practice will help to support the coordinated efforts required to sustain our frail older patients in the twenty-first century. The development and future growth of geriatric medicine will also depend on the continued evolution of our interprofessional partners in psychiatry, nursing, social work, and rehabilitation.

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Against a Duty To Die

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In a 2008 interview, Baroness Mary Warnock, a leading moral philosopher, said that people suffering from dementia had a duty to commit suicide: “If you’re demented, you’re wasting people’s lives—your family’s lives—and you’re wasting the resources of the National Health Services” [1]. Warnock also claimed that there was “nothing wrong” with helping people to die for the sake of their loved ones or society. Well known for her support of euthanasia, Warnock expressed in the interview the hope that people will soon be “licensed to put others down” if they are unable to look after themselves.

While such claims are controversial, they are persistent and seem to crop up from time to time in public debates and scholarly literature. In the United States, former Colorado Governor Richard Lamm expressed a similar view almost 30 years ago. Referring to the elderly as “leaves falling off a tree and forming humus for the other plants to grow up,” he told a meeting of the Colorado Health Lawyers Association, “you’ve got a duty to die and get out of the way” and “let the other society, our kids, build a reasonable life” [2].

In the scholarly bioethics literature, the most frequently cited reason for assigning a duty to die to old people is the utilitarian view that measures the value of lives by means of the amount of happiness or pleasure they contain. According to this approach, a duty to die arises when our lives have, on balance, more pain than pleasure. Since the elderly have on average fewer years ahead to live, their current misery is less likely to be offset by future happy years. Nonutilitarian justifications for a duty to die include arguments that it is wrong for the elderly to impose a burden that seriously compromises the lives of others [3]; that a duty to die is just a special case of a more general duty to prevent harm [4]; that old people living in wealthy nations have a duty to end their lives in order to transfer wealth to people living in poorer countries [5]; and that dying early represents a gift for others based on justice and reciprocity [6].

Social scientists have noted that the elderly often worry about being a burden on others, especially family members. In the period leading up to their deaths, elderly people who subsequently committed suicide reported that their lives had been lived and that they were now a burden on others [7]. Little is known about the experiences of elderly people who live and die alone, but in one qualitative study of this population, participants characterized a good death as being able to die without becoming a burden to others [8]. There is a small but growing body of evidence

suggesting that worry about creating a burden on others is common among people of all ages who are near the end of life [9].

Is the concern about burdening others well founded? In one sense it clearly is. Older people—and especially the oldest old (those age 85 and over)—have markedly greater functional and cognitive impairments than those in other age groups. In a retrospective analysis of population-based data from the Cambridge City over-75s Cohort Study, researchers found that at least half of subjects aged 90 and older needed “maximum assistance” in nearly every activity of daily living (ADL), with individuals categorized into overall disability levels based on their or their proxy’s responses to ADL questions [10]. Although more than half of the age 85-89 cohort needed no help in ADLs (such as bathing, showering, dressing, and getting to the toilet on time) or in other activities that were not physically demanding (such as using the telephone or taking medications), they still needed high levels of assistance with instrumental activities of daily living. These include tasks that support an independent lifestyle, such as preparing meals (39.6 percent), doing housework (45.3 percent), doing laundry (55.1 percent) and shopping (72.1 percent) [10]. Risk factors for dependency, such as “being unsteady on your feet,” were reported at high levels by all ages in the study population.

Since elderly people require more and more assistance as they grow older, are they right to be worried about becoming a burden? And, if they are, what follows? Is there a duty to die?

Addressing such questions requires us to think carefully about what it means to be a “burden” and why the frail elderly may be perceived as such. It is instructive in this regard to contrast the care of dependent people in old age with the care of dependent children. Being unsteady on one’s feet and needing help going to the toilet are characteristic of both the young and a subset of the old, and an infant requires total assistance with all activities of daily living, yet we view caring for the young and the old in strikingly different ways. Are infants a “burden” on parents, preschool teachers, and child care workers? We do not ordinarily think along these lines. Why is that? Clearly, more than the need for assistance enters into our perception of what qualifies as a “burden.”

Is it because mainstream bioethics, and moral philosophy more generally, tend to consider the autonomy and independence of mature adulthood as the pinnacle of human achievement? Not only is exercise of autonomy often considered in determining whether treatment of someone was just or right, it also functions in some theories as a prerequisite for the value and dignity of persons [11].

Elsewhere, I have argued that this way of thinking is fundamentally misguided [12]. It leads us, as we age, to loathe the qualities of dependency we see emerging in ourselves, to see them as “less than” the qualities a valued person has, and, therefore, to view them as unacceptable. It may also explain why we regard dependency in the very young as less burdensome than in aging persons: healthy children emerge from

their dependency to function independently; by contrast, elderly persons tend to experience a progressive decline of functioning as they age.

Since dependency per se does not establish that someone is a burden, much of our thinking is likely to turn on how we frame the moral status of those under consideration. I propose that the value and dignity of persons is intrinsic and does not depend on an individual's social or economic productivity. This view places the dependent and the independent on more equal moral footing. Likewise, if we agree that all human beings possess an intrinsic worth and dignity, then any utilitarian calculus that measures the value of persons by means of the amount of happiness or pleasure their lives contain is deeply flawed.

Rather than thinking of aging persons as a net drain on society, or an unfortunate “burden” to be borne by families, we should instead view them—as we do the very young—as deserving of our care. Moreover, since dependent people of any age can pose financial and time burdens on family members, society can and should intercede to ease family burdens and ensure that all dependent people receive the care they deserve. This means recognizing a binding obligation on the part of society as a whole to ensure that health care systems are structured in such a way that dependent people have access to caregiving services designed to ensure a threshold level of functioning and capability required for human dignity [12]. When society fails to meet its collective obligation, family caregivers often find themselves with financial and time burdens. But this is not unlike the situation of families with a single parent or two parents who have to work—caring for children imposes financial and time burdens. Under these circumstances, the elderly (and other dependent people) are right to worry about their needs imposing burdens. But this is neither necessary nor inevitable in wealthy countries, such as the United States.

In summary, I have argued that in a just society, the elderly would worry much less about being a burden. They would feel confident that society would afford them a basic level of care. When the elderly express concerns about being a burden, the proper response is not to suggest they have a duty to die. Instead, it is to commit to becoming a more just society. In the US, as well as in many other developed countries, there is not yet any public system offering long-term care insurance for the elderly. The Affordable Care Act signed into law in 2010 originally included a program of national, voluntary long-term care insurance, known as CLASS (Community Living Assistance Services and Supports). Although designed to be self-supporting, with monthly deductions from workers' paychecks, CLASS was opposed by critics who charged that it would add to federal budget deficits. In 2011, the US Department of Health and Human Services announced that the Obama Administration would not be implementing this program [13].

Encouraging elderly people to die, or helping them to end their lives, would certainly save money and free up resources. But this approach is neither ethically defensible nor necessary.

In the US and other developed countries, we are witnessing an unprecedented reduction in the proportion of society that is of working age, a development that has the potential to increase dramatically the burdens experienced by family members who care for the elderly. But it also has the potential to serve as a clarion call to action. As a society, we can and must do more to ease the burden on families and to give the old and young alike the care and commitment they deserve.

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Suggested Readings and Resources

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Virtual Mentor

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Theme Issue Editor

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