Old Age, Life Extension, and the Character of Medical Choice

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Objectives. This qualitative, ethnographic study explores the character and extent of medical choice for life-extending procedures on older adults. It examines the sociomedical features of treatment that shape health care provider understandings of the nature of choice, and it illustrates the effects of treatment patterns on patients’ perspectives of their options for life extension.

Methods. By using participant observation in outpatient clinics and face-to-face interviews, we spoke with a convenience sample of 38 health professionals and 132 patients aged 70 or older who had undergone life-extending medical procedures. We asked providers and patients open-ended questions about their understandings of medical choice for cardiac procedures, dialysis, and kidney transplant.

Results. Neither patients nor health professionals made choices about the start or continuation of life-extending interventions that were uninformed by the routine pathways of treatment; the pressures of the technological imperative; or the growing normalization, ease, and safety of treating ever older patients. We found a difference among cardiac, dialysis, and transplant procedures regarding the locus of responsibility for maintaining and extending life.

Discussion. Provider and patient practices together reveal how the standard use of medical procedures at ever older ages trumps patient-initiated decision making.

What is the character of medical choice in old age? This article examines how understandings of both old age and choice shape one another in the context of life-extending medical procedures. The desire for choice among medical treatments and control over clinical decision making is ubiquitous in large sectors of American society today, and the right to determine one’s own medical care has been an important feature of American life for the past 40 years. The great majority of physicians agree that the replacement of paternalism by treatment choice, which began in the 1960s and 1970s, has been a positive development. Older persons with access to medical information and treatments reap the benefits of this societal trend. But, perhaps more than other age groups, they also feel the responsibilities and burdens of an ever increasing number of treatment options, simply because in later life people have more chronic and life-threatening conditions—and thus there are more urgent and more difficult choices to be made. From the medical management of cholesterol, blood pressure, and heart disease to surgeries of all kinds; from the multitude of palliative or aggressive cancer interventions to drugs for depression, memory enhancement, and sexual dysfunction; from heroic life-extending procedures in hospital intensive care units to hospice care at home, older patients and their families have more options than ever before among standard, alternative, and experimental treatments; about how and whether to extend life and/or enhance its quality; and about the style and timing of death. These choices are, for the most part, wanted.

The appearance of autonomous decision making as a primary goal and value in American health care delivery has its roots in various historical developments in mid-20th century medicine and cultural life, including the emergence of rights movements of all kinds (women’s, patients’, disability, etc.); the consumer movement in health care (Berliner & Salmon, 1980); the technological imperative in medicine (Fuchs, 1974; Koenig, 1988); the expansion of subspecialization in the clinical fields; the dominance of procedure driven reimbursement schemes of third party payers; and, perhaps most pointedly, the rise of bioethics as a disciplinary force in medicine (Rothman, 1991). The emphasis in bioethics on the importance of individual decision making, informed consent, and the doctor–patient dyad has had a remarkably powerful impact on doctor–patient and hospital–patient relations (Fox, 1991).

The overwhelmingly positive value accorded to choice is accompanied by an exponential growth in the United States, during the past 15–20 years, in medical interventions in late life (Interdisciplinary Leadership Group, 2000; Solomon, Burton, Lundeberg, & Eisner, 2000), and there is a growing literature on the justification and benefits of performing many kinds of procedures on persons older than age 80 (Christenson, Simonet, & Schnuziger, 1997; Craver et al., 1999; Hricik, 1991). Together, the availability of more options at ever older ages and the normalization of life-extending, life-enhancing treatments at older ages promote the notion that aging and death are not inevitable and foster the assumption that one can, and should, choose to intervene. (The assumption of intervention in late life is not as pervasive in Europe, where the limitations to health care resources are widely acknowledged. [See, for example, Dey & Fraser, 2000; Mariotto et al., 1999].) There are no longer steadfast clinical assumptions, in the United States, about technological or biological limits to what one can do, medically or surgically, for older persons. Furthermore, intervention leads to more intervention because natural age limitations for procedures are no longer thought to be inevitable. It is well
known that, when assessing treatment options, geriatricians (and other clinicians as well) understand chronological age to be merely one factor among medical, functional, and social variables (Solomon et al., 2000). Patients, for their part, have become medical consumers responsible for questioning after and determining (to the extent possible) their own health, longevity, and death. Medical choice contributes to the reframing of old age. In addition, societal conceptions of old age and a “normal,” “natural” life in old age are changing the way medicine is being practiced (Estes & Binney, 1989; Kaufman, Shim, & Russ, 2004).

Three features of choice remain below the surface of medical and consumer discourse and thus are not fully appreciated for the ways in which they influence the delivery of medical care today and for the ways in which they determine societal understandings of health, illness, old age, and medical and familial responsibility. First, health professionals limit the actual choices patients can make by the treatments they offer to patients in hospital, outpatient, nursing home, hospice, and other clinical settings (Drought & Koenig, 2002; Kaufman, 2005; Lynn et al., 2000). Those offerings, in turn, are determined by Medicare reimbursement regulations to hospitals and physicians, the specter of litigation that looms over much of medical practice today, the structure of specialist medical practice and clinical practice guidelines, the patient’s particular insurance coverage, and the physician’s own priorities about what needs to be done. Consumer demand for specific procedures can broaden choice, but ultimately structural realities as well as the patient’s medical condition place practical limits on what procedures are available and what can be done.

Second, in many cases, standard treatment subverts choice because options are rarely equally weighted. For example, a person who arrives at a hospital emergency department with severe chest pain and shortness of breath is taken for an angiogram and told he or she needs immediate cardiac bypass surgery or the placement of stents because the risk of death is high. The patient and family readily consent to the procedure. In these circumstances, it is a rare patient who would choose otherwise. This replacement of choice with standard-of-care medical action occurs for three reasons. First, when procedures are tried out on older populations and are shown to be effective at ever older ages, they become routine (Koenig, 1988) and, thus, expected and desired by clinicians and patients. Also, when techniques become less invasive and associated with lower mortality risk, both consumer demand for them and ethical pressure to make them available increase. Finally, procedures that are relatively low risk (angioplasty, stents, dialysis) quickly become standard practice. This thereby eliminates actual clinical choice about whether to refuse these procedures. Together, these features of procedure driven medical care contribute to the difficulty—for patients, families, and health professionals alike—of saying no to treatments, even for patients of very advanced age.

Third, many patients cannot or will not articulate preferences about what they want in the way of specific treatments, perhaps most especially when they are at risk of death. Importantly, neither patients nor families can easily imagine a particular future of specific medical symptoms, evaluate whether life or death is desirable given those symptoms, and then choose between such a life or death. Neither do they always understand the distinctions among medical options. Often seriously ill persons make treatment choices, only to change their minds later (Kaufman, 2005). Investigators in one large study of end-of-life treatment decisions found that neither patients nor families wanted the responsibility for such decision making and that they “often delayed or dodged making a choice” at all or simply went along with usual hospital practice (Lynn et al., 2000, p. 218).

In order to understand the ways in which these three features of choice work for health professionals and patients, we examined the parameters of clinical decision making that both providers and patients describe. (We are well aware that choice, autonomy, medical decision making, and health care consumption are highly constrained, or entirely absent, among those persons without access—via Medicare, Medicaid, or private health insurance—to the array of life-extending treatments currently available.) This article has two aims: (a) to describe the sociomedical features of treatment that shape provider understandings of the nature of choice—and no choice; and (b) to illustrate the effects of treatment patterns and provider practices on patients’ perceptions of their options for treatment and for life extension.

We investigated choice in the context of three kinds of medical therapies: (a) cardiac procedures employed to reduce pain, the chance of heart attacks, or sudden death (i.e., angioplasty, coronary artery bypass graft, stent, and the automatic implantable cardioverter defibrillator (ICD)); (b) kidney dialysis; and (c) kidney transplant. We chose these three kinds of treatments because they are emblematic of the rising age for medical interventions of all kinds, their use is already routine (and becoming more common) at the oldest ages, and they exemplify both the successes of life extension and the responsibilities and burdens of medical choice for health practitioners, older persons, and older persons’ families in American society today. We briefly describe the recent history and context of growth for each kind of therapy, which provides the conceptual and practical frameworks both for health provider considerations about what to offer and what needs to be done, and for the extent of patient decision making.

**Background Features Determining the Character of Choice**

All framing of medical choice for older Americans is determined, first of all, by Medicare and other third party payer reimbursement schemes, which serve as background to specific decision making (Kapp, 2002; Rice & Fineman, 2004); and, secondly, by the growing safety, reduced risk, and concomitant normalization of these (and other) procedures at ever older ages. Each of the three kinds of therapy we investigated exists in its own sociomedical environment of broadening criteria and pressures for intervention.

**Cardiac procedures.**—Coronary artery bypass surgery is now commonplace for persons in their 80s and is not unusual for persons in their 90s (Glock et al., 1996). Its safety profile has vastly improved in the past four decades. There has been tremendous growth in the use of stents in the past decade, increasing from 85,000 procedures among those aged 65 and older in 1996 to 233,000 in 2000 (Kozak, Hall, & Owings, 2002). Physicians implant defibrillators into approximately.
of life and are sometimes performed into the early 80s. Cadaver transplants are no longer unusual in the seventh decade; Organ Procurement and Transplantation Network, 2004). The situation is similar in Europe (Schratzberger & Mayer, 2003). Transplants are no longer unusual in the seventh decade of life and are sometimes performed into the early 80s. Cadaver kidneys from donors older than age 50 are sought and are available so that they can ease the shortage of transplantable kidneys for older recipients. In addition, living kidney donation is on the rise for all age groups, exceeding cadaver donation for the first time in the United States in 2001 (Organ Procurement and Transplantation Network, 2004).

**Methods**

The findings we report here are drawn from a larger descriptive, qualitative anthropological study of the use of life-extending medical procedures among persons aged 70 and older in California. The study received Institutional Review Board approval from the Committee on Human Research at the University of California, San Francisco. The overall two-part goal of the larger study was to investigate (a) how physicians, patients, and patients’ families enter into and understand the use of these three kinds of life-extending medical procedures, and (b) how life-extension practices and the sociomedical developments surrounding them are impacting geriatric medicine and the health care of older Americans.

**Data Collection**

We collected the data reported here in 2003 and 2004 by using the two classic methods in sociocultural anthropology: open-ended interviews and participant observation (Hammersley & Atkinson, 1995). We conducted formal interviews and informal conversations with physicians in the cardiac fields in their offices, with dialysis health professionals in their offices and clinics, and with cardiac and transplant patients in their homes. We conducted participant observation in dialysis and transplant clinics. That is, in each clinic setting, we observed staff–patient or staff–patient–family interactions and entered freely into discussion with patients, families, and staff both before and after staff–patient conversations. In the dialysis clinics, we observed patients receiving dialysis, staff caring for patients, and predialysis clinic meetings among staff, patients, and families. In the transplant clinics, we observed the first phase of the transplant evaluation process, in which patients and (often families) meet with physicians, nurses, social workers, financial staff, and dietary staff in order to assess the patient’s medical eligibility for transplant and social context for surgery and recovery, and to discuss potential donor types. Together, interviews and conversations with mentally competent patients and their providers ranged from 15 min to more than 1 hr in length, depending on the stamina of the patient and the time available to patients and providers in clinics and homes. When appropriate, we tape recorded these conversations (and later transcribed them verbatim); otherwise, we took extensive handwritten notes.

Our goals in the clinics were to pay attention to the everyday, ordinary practices and conversations we witnessed, and to observe and follow the pretreatment and treatment processes with regard to patient and provider understandings about choice. Our interviews and conversations followed the tenets of ethnographic interviewing (Spradley, 1979) meaning we organized the topics for discussion but did not use a pre-determined set of specific questions. For providers, topics included: rationales for treatment, standard treatment, clinical responsibility, and the relationship between advancing age and

Kidney transplant.—The number of kidneys transplanted to people older than age 65, from both live and cadaver donors, has increased steadily in the past two decades in the United States. According to the 2003 annual report of the Organ Procurement and Transplantation Network, 1,684 persons in the United States aged 65 and older received a kidney transplant in 2003 (11.1% of the 15,135 total kidney transplants that year; Organ Procurement and Transplantation Network, 2004). The situation is similar in Europe (Schratzberger & Mayer, 2003). Transplants are no longer unusual in the seventh decade of life and are sometimes performed into the early 80s. Cadaver

Dialysis.—The context for choice about renal dialysis therapy is shaped by the 1972 law extending Medicare benefits for dialysis to all individuals with end-stage renal disease. In the years since, the criteria for dialysis selection—once stringent—have loosened and, over time, largely fallen away. At the same time, advances in dialysis care mean that physicians are now more successful at dialyzing patients (including many older patients) with complicated disease states. These combined developments have led to a treatment milieu in which physicians usually consider dialysis appropriate for all end-stage renal disease (ESRD) patients, and in which they mostly feel that it is morally unjustified not to offer dialysis to any patient with ESRD. Consequently, doctors routinely dialyze ever older individuals in hospitals and outpatient centers across the United States, and there has been a progressive graying of the dialysis population. In 2001, in northern California, patients between ages 65 and 79 made up 34% of the overall dialysis population, and patients older than age 80 comprised 10% of this same population (Transpacific Renal Network, 2001). Projected trends for the next 10 years indicate an increasing proportion of new dialysis patients older than age 75 (Jacobs & Mignon, 2002). The goals of treatment, however, have not evolved from half a century ago to reflect this shift in the demographics of the patient population. With few exceptions (Cohen, Germain, & Poppel, 2003), the medical literature has not addressed the role of palliative care and the acknowledgment of the nearness of the end of life in these settings, which indicates that clinicians are disinclined to discuss death with patients, thereby curtailing the choice of death over dialysis as a specific medical option (Perry, Swartz, Smith-Wheelock, Westbrook, & Buck, 1996).

**METHODS**

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the uses and efficacy of treatment. For patients, topics included: retrospective accounts of how they came to use treatments; the extent to which they sought treatment; the extent to which they sought changes in treatment or additional treatments; influences on decision making, if any could be discerned; and kinds of decisions made. Our observations of treatment patterns and conversations together enabled us to discern the characteristics of choice described here.

Sample
We drew both provider and patient study participants from an opportunistic, convenience sample generated by a traditional snowball approach (Miles & Huberman, 1984), in which we asked health professionals for referrals to other providers and to patients. We conducted formal interviews and repeated informal conversations in clinics with the following individuals: 16 physicians in the cardiac fields (solicited from different specialties and practice settings) and 28 persons who had received one or more life-extending cardiac procedure in the past several years; 18 health professionals (physicians, nurses, social workers, and administrators) working in the field of renal dialysis and 43 patients currently in hemodialysis treatment at outpatient clinics; and 33 kidney recipients, 28 persons in the process of medical evaluation for a kidney transplant, and 4 health professionals (1 physician, 1 nurse, and 2 social workers) at transplant clinics.

In all, we spoke at length with 38 health professionals and 132 patients (77 men, 55 women). Sample size reflects saturation of themes (Strauss & Corbin, 1990) on the topic of choice vis-à-vis the medical procedures studied (see Ethnographic Analysis, below.) All patients were between the ages of 70 and 93 at the time they underwent medical procedures. Ethnically, our entire sample of past, present, and prospective patients reflected the broad ethnic diversity found in metropolitan California: African American; Euro-American; Chinese American; Japanese American; Hispanic; Filipino; Samoan; and immigrants from Afghanistan, China, Western and Eastern Europe, the Philippines, and Vietnam. Our sample of health professionals, though not as diverse, included African American, Euro-American, Latino, and Asian American practitioners. In addition, we had many brief conversations during the 2-year period with other health providers in the clinics and with other patients younger than age 70. We have omitted here discussion of data from interviews with families for reasons of article length, yet, as we will note, families often shared explicitly in decision making. In addition, the existence of family was frequently the reason patients chose to go forward with life-extending treatments.

Ethnographic Analysis
Our intent is to illustrate, for these procedures and among older patients and their providers, how choice is broadly understood and characterized. In addition, this study is about the meanings surrounding the increasing use among elders of life-extending medical procedures. We derived our findings from repeated readings, by all authors, of selective field notes and interviews pertaining to the overall topic of choice. We identified core substantive categories (also called codes or themes) that reappeared in the data often (Miles & Huberman, 1984; Strauss & Corbin, 1990). Codes “pull together and categorize a series of otherwise discrete events, statements, and observations which they identify in the data” (Charmaz, 1983, p. 111; see also Kaufman, 1986; Luborsky, 1994; Strauss, 1987). For providers, codes included: constraints on choice, the technological imperative, standard practice, relationship of risk to age, and changing trends and techniques. For patients, codes included: medical condition and context of procedures, perceived treatment options, family and other influence, and reflections on agency and passivity. These and other codes generated our results and interpretive scheme. We performed successive phases of coding until we reached 95% agreement among all authors on core codes relevant to the topic of choice and on highly representative provider and patient quotations used in this article. Our results reflect provider and patient descriptions of what choice means and how it operates in today’s sociomedical climate.

RESULTS

Providers: The Organization and Parameters of Choice

Cardiac procedures.—All physicians that we interviewed noted three factors that influenced their thinking about offering procedures to older patients, influenced their thinking about performing these procedures on older patients, and guided them in persuading patients to undertake or decline specific interventions. These factors were that (a) the age at which interventions are routinely performed has increased in the past two decades; (b) many procedures have become less invasive, safer, and less risky; and (c) the chain of specialist and subspecialist referrals has led to increasing numbers of interventions on any one patient becoming standard practice.

Physicians spoke about the overwhelming success of bypass surgery for patients in their 80s, noting that even very sick and very old patients now benefit from the procedure. One cardiac surgeon noted, “The great majority of patients, even though they’re older, do very well. I’m continually astounded by the patient who is 80 years old, and you operate on him and he goes home of the fourth day.” Another said, “We are doing more, and we’re getting much better results than we were in the old days.” Physicians agreed that clinical responsibility means performing procedures if potential benefits are thought to outweigh risks, regardless of age.

Physicians discussed the fact that noninvasive treatments almost always pave the way for additional, often more aggressive, procedures. In addition, aggressive procedures pave the way for less aggressive ones. Many physicians we interviewed described both types of intervention as a “technology parade,” in which cardiologists, then cardiac surgeons, and finally electrophysiologists (who implant ICDs) each provide a life-extending procedure that is, in part, facilitated by the one that came before. For example, catheterization is routine procedure in most hospitals when cardiac symptoms are present. Angiograms show blockages that are treated with angioplasty, stents, or bypass surgery. Doctors assess future risks and indicate, and thus implant, ICDs. Several physicians compared the escalation of intervention to a speeding train: nearly
impossible for patients and their doctors to jump off. A cardiac surgeon noted:

Once you’ve got that stent, it gets progressively harder to pull back from sending the patient onto someone like me. By the time they get involved with me, I mean, the train’s going down the track about 75 miles an hour. And I walk in, and the patient is a surgical candidate, and everyone is pretty well committed to it. And that’s what sweeps them up. And they don’t hear the issue of, “Do you know how bad you’re going to feel and how long it’s going to take you to feel well?”

The specialist and subspecialist referral process is pivotal, we found, for determining whether patients ultimately undergo cardiac interventions. When internists and cardiologists think that angioplasty, stent, or bypass surgery are potential options, they recommend further consultation with interventional cardiologists and cardiac surgeons who perform those procedures. When such referrals are made, rarely do patients refuse, and rarely do those consulting specialists then recommend against the use of those procedures. One interventional cardiologist summarized the view of others we interviewed:

If the patient meets the clinical criteria that would allow them to have a defibrillator, I would never absolutely refuse to offer it to them. ... I mean, I’m going to kind of bite the bullet and do what I know how to do and get them through this, and then leave the rest for them to live with that decision since we’re not talking about a procedure that has significant life-threatening risks that come with it.

Conversely, when internists and, less often, cardiologists recommend medical management, patients are tracked into clinical pathways that often do not include angioplasty, stent, or bypass as options. Thus, rather than being used as consultants or informational resources in the process of decision making, the decision nodes of referrals—that is, the points at which patients are passed on (or not) to increasingly subspecialized and often intervention-oriented practitioners—actually serve as proxies for provider or patient decisions to undergo these procedures. When physicians actually offer a choice to patients about having a procedure or procedures, they are able to persuasively guide the patient toward medical action (“Without a bypass, you are a sitting duck for a heart attack...”) or toward one kind of treatment (“Stents are less risky than bypass...”). Rarely do they offer no treatment as an option. Many physicians we interviewed spoke of how “enormously persuasive” they could be and of how “patients’ opinions are greatly influenced by the person presenting the options” and “the ways options are presented.”

As growing numbers of elders receive more kinds of interventions, “the extravaganza of cardiology,” as one doctor put it, becomes an increasingly accepted and “natural” part of old age. For practitioners and patients alike, that trend influences the absence of deliberation about whether to treat. Instead, treatments become standard practice among elderly adults, and standard practice trumps choice.

Dialysis.—There are two predominant clinical pathways to the initiation of dialysis. It begins either in the hospital as standard, necessary treatment following a life-threatening acute episode (when patients may be comatose or otherwise unable to deliberate about treatment options), in which case there is no specific decision about it. Or it starts following one or more outpatient visits to health professionals who inform patients that kidney function is worsening and that dialysis is, or soon will be, necessary in order to live. The latter pathway does not involve much, if any, choice either. Instead, choice is replaced by preparation for dialysis treatment. In the clinics we observed, physicians and other staff framed the need for dialysis in terms of “when you will need to start dialysis,” not if. The only clearly discrete moment of choice occurs around the discussion of fistula or graft placement (in their arm, to accommodate the dialysis needles) as a “preventive measure, should patients need or choose,” providers say, to initiate dialysis at a later point. Thus, health practitioners present the preparation for dialysis as a preventive measure. And they discuss fistula placement as a “very minor procedure,” almost a nonprocedure, thereby minimizing the need for choice in the first place and simply eliding choice about “the potential need to start treatment” with preparation for the treatment itself. At one clinic we observed, nephrologists appealed to family ties in order to get patients to choose to prepare for dialysis. For example, one physician said to a patient, “Don’t you want to continue living for your grandson? Don’t you want to see his children—don’t you want that for him? If you want to see his kids, you have to get a fistula this summer...” Encouraged in this way, patients agree to fistula placement.

Often, getting patients to start dialysis is a subtle matter of negotiation, and doctors do not push patients to begin dialysis against their will. A physician in one predialysis clinic noted that he “prepared” patients (and their families) for dialysis with discussions over the course of several weeks or months. He spoke about “building trust” and said he bargained with patients, asking them repeatedly to consider dialysis, that it might be a necessity later. He and others spoke of dialysis as a possibility in the future. In that way, he normalized it as a required and ultimately inevitable treatment.

A social worker with a great deal of experience at one clinic described the force of dialysis clinic culture, which guides provider and thus patient choice.

Everyone has the right to dialyze. Nothing disqualifies patients today. When dialysis first started in the 1960s it was selective medicine. Now, there is a drive to keep people alive longer. Period. They are just placed on dialysis and told that this is what we need to do. It is automatically assumed that a patient wants dialysis. “No” is never presented as an option. I think patients find out that saying “no” is an option only when they read the pamphlets we hand out. That’s how “choice” is discovered. Most doctors do not actually say, “By the way, there is the option of no dialysis.”

Discontinuing dialysis is characterized by the absence of choice as well. Dialysis clinic staff do not typically initiate discussions with patients about death or about stopping dialysis. Indeed, nationally, only 7.5% of dialysis patients older than age 65 voluntarily withdraw from treatment (Levinsky, 2003; U.S. Renal Data System, 2001). If patients ask about it at all, health practitioners tell them that they can always choose to discontinue dialysis in the future. Thus, most often family and medical staff make discrete decisions about stopping treatment as a response to multisystem organ failure when patients are...
comatose and death is clearly imminent. The culture of the clinic does not prepare elderly patients for this eventuality, or for the option of stopping treatment before emergency hospitalization and organ failure occur. On the infrequent occasion when a patient does bring up the subject of discontinuation in the clinic, staff generally interpret patient remarks as a sign of clinical depression and thus put into play specific treatment decisions for depression.

**Kidney transplant.**—In the clinic, providers generally mention three options for transplant during their discussions with patients and families: (a) a kidney from a deceased donor (with a 4–6 year wait); (b) a kidney from an older (aged 50 and older) deceased donor (with a 1–2 year wait); (c) a kidney from a living donor. Some physicians guide patient and family decision making by emphasizing the shorter waiting period for a kidney from an older deceased donor and by suggesting or encouraging living donation. Persons older than age 70 may become ineligible for a transplant if they wait too long; that is, they may become sicker if they remain on the 4–6 year United Network for Organ Sharing waiting list for a cadaver organ. The older one is, the more precarious one’s health may become in a few years, and thus the greater urgency to undergo transplant surgery while one is still able to withstand the surgery and have a positive outcome. The wait for a kidney from a cadaver donor older than age 50 or 60 is not as long as the wait for a “younger” kidney, and there is virtually no wait for a kidney from a living donor.

Patients and families quickly learn that their choice must take into consideration these transplant realities regarding time and age. For instance, as one physician said to a 77-year-old man with heart disease, “Realistically, you’ll have to have someone donate you a kidney if you have a chance of getting one.” Another physician said to a 71-year-old woman, “I think getting you a kidney would be a great thing. But the sooner the better. It could be 5–6 years if you wait for a cadaver donor, especially because of your blood type.”

Although the health professionals we observed always indicated to patients that a kidney transplant carried some risk and that living with a transplant would not eliminate all health problems or the lifelong need for medications, they did stress that a transplant would free the person—as nothing else could—from the physical side effects and functional limitations of dialysis. If physicians consider a patient to be a good candidate for transplant, regardless of age, life extension and better quality of life are available (Wolfe et al., 1999). Patients make choices in this context.

**Patient Perceptions of Choice**

**Cardiac procedures.**—The 28 patients we interviewed described a range of perceptions of choice about undergoing angioplasty, stent, or bypass procedures. Their retrospective accounts were in agreement with physician comments that, for the most part, a patient’s medical condition in the context of sociomedical factors determines the start and extent of treatment. We could place patients’ interpretations of events on a continuum in which they described (a) having no choices, (b) making decisions among some options offered by physicians, and (c) setting the parameters for choice themselves. Some patients had had multiple procedures during a period of years so that, depending on the procedure, patients described one or more experiences of choice/no choice in their interactions with the health care system.

In formal interviews, 20 patients noted that they had made no decision about initiating most treatments. Their doctors had told them what was needed, they trusted their doctors, and they did not refuse procedures, which simply “happened.” In some of those cases, the patient’s near-emergency condition and subsequent diagnosis precluded patient choice entirely. For example, one woman said she had an angiogram as part of her regular medical care and, when it revealed severe blockage of six vessels, she was admitted to the hospital right away and scheduled for surgery “without my permission.” She said little information was given to her about bypass, stents, or risk of procedures. Other patients recalled that they were told that “surgery is the only option,” or that they “required surgery,” or, as an 89-year-old man said, “As it was put to me, if I don’t have the bypass tomorrow morning, I won’t live six months. So there wasn’t really an option. The risks—minor strokes, major strokes—went through my head in fifteen seconds. It’s not a question of considering risks. It was offered, and I was taking it.” For the most part, these patients chose in the sense that they did not refuse treatment for what they were told was a life-threatening or high-risk condition. Because of their desire to live, they felt there was no other option.

Ten patients (including 4 from the group mentioned in the preceding paragraph) recalled that they did make some decisions about when to undergo a first cardiac treatment or about follow-up procedures years later, but that their options had been specifically circumscribed by their physicians. For example, 2 patients, when told they needed bypass surgery, deliberated for years before going ahead. Others, when offered angioplasty or stents, consented to those procedures but wondered after the fact if bypass (which had not been offered) would have been more effective.

Eight patients (including 5 from the group mentioned in the preceding paragraph) deliberately controlled the timing of bypass surgery or decided which procedure they would have. For example, one patient decided very early in his disease trajectory that he would have a bypass, before it was suggested by his doctor. Another sought out a surgeon who would perform a bypass because his regular physicians did not recommend it. A woman consented to angioplasty only, but not to emergency bypass if that was needed. Sometimes patients were caught between two medical points of view. One man with severe symptoms noted that one cardiac surgeon refused to perform a second bypass operation because his health problems made him a high mortality risk, whereas another surgeon was willing to do the bypass. This 75-year-old man noted that the second surgeon said that his “chances were not great, but were fairly good.” In this case, the patient had a choice to make, and the stakes were high. He postponed making any decision and said that he viewed “medical management” of his condition as a “nondecision, as a default” in the face of feeling unable to be proactive about bypass surgery.

**Dialysis.**—Of the 43 dialysis patients we interviewed, only 2 expressed their initiation of dialysis treatment as a proactive
decision. Most insisted that there was “no decision—it just happens.” The assumed certainty of death without dialysis trumped any risk–benefit analysis or decision making process. “I had no choice” and “I wanted to live” was what all patients matter-of-factly reported.

At least 4 patients did not have a choice initially: They landed in the hospital, extremely ill, not fully conscious, and staff placed them on dialysis as part of standard life-saving medical treatment. “They just wheeled me down there,” said one patient, referring to the acute hemodialysis unit to which she was taken after her kidneys failed during open heart surgery. This patient, who had “never wanted to be kept alive by a machine,” emphasized her exclusion from the decision making process: “The doctors pretty much made the decision, and my son agreed.” A dozen other patients said that they felt sick, went to the doctor who told them they were in kidney failure, and were put on dialysis in the hospital that same afternoon or the following day. All of these patients experienced the start of dialysis as treatment for an acute illness episode, making no decisions on their own.

In the outpatient clinic, the more common of the two pathways through which dialysis was initiated, patients typically resigned themselves to the incremental steps and procedures that led to dialysis without actually choosing to start therapy. For example, patients agreed to periodic blood tests that track the loss of kidney function; to be fitted for a fistula as a precautionary measure; to talk to the dialysis social worker; and, finally, to start treatment. Thus, discernible decisions about initiating dialysis therapy for ESRD were preempted by these earlier and comparatively unremarkable actions that anticipated and justified the decision to begin. Most patients in our sample had had at least a few visits to the predialysis clinic in which they were prepared for treatment. Among these patients there was a broad range of attitudes about choice and control, from feeling that the situation was “out of control” to emphasizing that they were taking control of their disease by acquiescing or agreeing to treatment: “I decided with my kids that this was the only/best option.” Patients also expressed varying degrees of resistance to starting therapy, from “I won’t even consider it” to “I really don’t want to do this.” Once dialysis was underway, some noted that the choice was between accepting the routine of treatment and “surrendering” to it or “making it a shock and trial” each time you came to the clinic.

Any proactive decision making by patients, if it occurred at all once dialysis had started, was focused on balancing desired longevity with diminished quality of life and with the probability of increasing complications due to multiple chronic diseases (and, thus, greater suffering). A 72-year-old man in our sample, who was unusually proactive, made decisions about his treatment schedule that would enhance his quality of life, despite the fact that options were never offered to him. Against the recommendation of his doctors he completely eliminated one day of a 3-day per week treatment schedule. Occasionally he did not come to the clinic on a second day. He insisted to all that he felt better (“less tired, less washed out, more able to work”) on the days that he did not come to dialysis. When he did come, he bargained with the staff about how much time he was willing to be hooked up to the machine and how much fluid should be taken off. He considered discontinuing dialysis. His range of activism was rare. Only about 10 of the 43 patients we interviewed in the clinic framed any of their comments in terms of their own proactive agency.

The question of how treatment ends, and through whose agency, is one that hovers over treatment and emerged often in patients’ narratives about remaining alive on dialysis because they had no clear or foreseeable end to their experience. For instance, some patients questioned whether and when the therapy would lose its effectiveness, and one man asked, “Do people reach a level of satiety, after which the treatment is no longer effective or maxes out, or after which they simply can’t sustain it any longer?” Others, concerned about declining health and function with advancing age, asked, “How long can people last on dialysis?” And, “What kinds of conditions or events lead to eventual decline, even on dialysis?” About 10 patients articulated the possibility of discontinuation with the question: How long do I want to live like this? For example, one woman, who insisted that she agreed to dialysis only for the sake of her husband and son, asked when it would be permissible to “say enough.” When she said, would she have “tried hard enough, suffered enough to have earned” her death? She implied that she had reached, or nearly reached, the moment when the benefits of treatment had been overcome by physical suffering. For other patients, the possibility of discontinuation was articulated in a more hypothetical context. One man said that discontinuation was his “ace in the hole” should the difficulties and rigors of treatment become too much for him in the future. He commented, “Not a lot of people have that control.”

Kidney transplant. —Because the overwhelming majority of patients who arrive at a transplant clinic for an initial evaluation have already made the decision that they do not want to start or remain on dialysis, they are faced with the three options for kidney donation that transplant medicine provides: a deceased donor with a years-long waiting list, an older deceased donor with a shorter waiting period, or a living donor from their own social network. The 33 transplant recipients and 28 prospective recipients we spoke with articulated a broad range of opinions about the desire to ask for and accept an organ from a living person, the obligation not to ask and not to take, and the responsibility either to wait years for a cadaver donor or to quickly solicit from among potential living donors. We observed a range of engagement styles with transplant medicine, from proactive self-education about transplantation, discussion with physicians, and strategic avoidance of dialysis to passive acceptance of whatever treatment a physician recommended. Among our interviewees, neither ethnicity, immigrant status, nor gender determined the ethics and practice of seeking or accepting an organ (living or cadaver).

Some people wanted a kidney transplant as soon as (or before) they learned they had ESRD, and they lined up prospective donors before their first visit to the transplant evaluation clinic, even before talking with health professionals. Some of them organized a list of potential living donors in order to avoid starting dialysis at all, and regardless of whether their physicians suggested or offered transplantation as a treatment. Five patients said their community doctors told them to begin or remain on dialysis; they, however, were adamant about receiving a transplant and ignored that medical advice. For others, the possibility of a transplant dawned slowly, over
a period of weeks, months, or years after dialysis began. Those in this latter group came to the transplant clinic for a work-up and evaluation, not necessarily because they felt ill or sought a transplant, but rather because their primary care doctor or renal specialist suggested that they do so. They were put on the national waiting list for a cadaver donor. At that time, they may (or may not) have considered a living donor, even though some of them did not necessarily seek or want a transplant. The most passive actors were those who waited years and eventually received a cadaver donor kidney. For example, a 70-year-old scientist with a wife and six children said:

When I was diagnosed with kidney failure, the nephrologist decided to put my name on the transplant list, even though I didn’t really have any intention of having a transplant. Then, as long as the hemodialysis was working out, and I had accepted that as an alternative to transplant, I really didn’t think much about having the transplant. I just accepted going through the routine of having these things done, in preparation for a possible transplant, but still, never with the idea of undergoing the procedure myself ... But the reason I went ahead with it was because it was available, it was an option.

People who actually made proactive decisions of some kind with regard to seeking or accepting a kidney from a living donor expressed a range of ethical imperatives that had framed their choices. For example, from those who refused to accept a live donation we heard:

The only thing they asked me in the clinic was, did I have anyone in the family who was willing to donate a kidney for the transplant? My nephew was willing to donate, and I said, no way, I wouldn’t do it. If his other kidney failed, he would have been in trouble. It is not worth saving my own life to take on that moral burden. I waited for a cadaver kidney, and I waited five years.

In contrast, from individuals who actively sought donors, we heard:

I was willing to be on dialysis, I didn’t know anything about it ... But then I hated it and wanted to get off it. In the beginning, my doctors did not offer or discuss transplant. When I learned, two years later, that I wouldn’t have to wait around on dialysis if I had a live donor, my wife lined up 14 people who would donate. You have to be proactive. You can’t just sit around, or you’ll die waiting.

There are intermediate ethical positions, as well, between outright refusal to accept a living donor organ and proactive solicitation of one. The ethical criteria and basis for deciding to accept a kidney from a living donor—and how wide one will outright refuse to accept a living donor organ and proactive solicitation of one. The ethical criteria and basis for deciding to accept a kidney from a living donor—and how wide one will have been in trouble. It is not worth saving my own life to take on that moral burden. I waited for a cadaver kidney, and I waited five years.

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There are intermediate ethical positions, as well, between outright refusal to accept a living donor organ and proactive solicitation of one. The ethical criteria and basis for deciding to accept a kidney from a living donor—and how wide one will concede the net beyond spouse, siblings, or children in pursuing a living donor—are idiosyncratic and often change as the patient gets sicker, adjusts to the routine of dialysis, or receives unanticipated offers of a kidney.

**DISCUSSION**

Our goal has been to explore the black box of medical choice for practitioners and elderly patients by illustrating how choice is organized, constrained, and mobilized with regard to three kinds of life-extending therapies. We illustrated how the structural realities of health care delivery in the United States, the relative ease and safety of performing procedures, and the sociomedical difficulty of not offering and not performing procedures combine to create the parameters for decision making and the range of negotiation and activism that are possible. Provider and patient comments and practices together exemplify how, for the most part, the standard use of procedures at ever older ages trumps patient-initiated decision making.

An important feature of this constrained nature of choice is that it is infused with hope and with faith in technology and medical action. Both cardiac procedures and kidney transplant at older ages are powerful examples of ways in which hope is realized through procedures, regardless of whether patients make active choices about them. Both interventions allow life and enhanced quality of life while preventing risk, debility, and death. They are exemplars of maximizing life’s potential. Beneficiaries of both kinds of treatments told us that “they feel 10 or 20 years younger” since having had the procedure.

Chronic dialysis in late life is entirely different and is, perhaps, the quintessential example of a procedure severed from hope and a therapy that, although it extends biological life, does not maximize what any patient would consider a good or full life. The character of choice in the case of dialysis, then, reflects an adaptation to the demands of the therapy itself and an acceptance of a diminished life. This fact wreaks havoc with many patients’ experience and desire to continue treatment and continue living.

We also found a difference among the procedures regarding the locus of responsibility for maintaining and extending life and the reasons invoked for choosing life extension. In the case of the cardiac procedures, the physician, as specialist and technician, provides a preventive or risk-averting safety net to patients via the techniques available. The notion of risk powerfully dictates clinical responsibility in the cardiac fields and, thus, deciding to treat risk is a doctor’s responsibility. Because mortality and morbidity are often low risks with these procedures, even at older ages, intervention is seen by physicians and patients to be relatively “free” and thus not hard to choose. In the case of dialysis, providers emphasize the certainty of death, rather than risk, if patients with ESRD do not undertake ongoing dialysis treatments. The prevention of death is valued above all else in the dialysis clinic, even if it comes with increased suffering in the face of exacerbating illnesses. Our dialysis patient interviews revealed an unresolved tension between, on the one hand, the value of bodily life-prolongation per se and, on the other hand, the ambivalence about remaining alive. Patients gain extended time through physical and emotional hardship and, thus, pay for life with life. Overwhelmingly patients felt a responsibility to maintain life and to do the work that would keep them alive. In the case of kidney transplant, the locus of responsibility sat strongly with patients as well. Even the most passive patients, who would not or could not proactively choose among donor types, illustrated their decision to consider transplant surgery instead of chronic dialysis when they made an appointment and then came to the evaluation clinic (sometimes from very great distances). They decided to undergo transplant surgery when their name came to the top of the waiting list or when someone offered them a kidney. The increase in living donations shows that, in this
example, responsibility for the life of the patient is assumed also by kin and friends who offer and give up their kidneys to maximize someone else’s life.

Another sociocultural feature of American society underlies and shapes the possibilities for medical decision making. There is a willingness to allow a level of intervention into our own bodies—to experiment on ourselves—that is unprecedented (Clarke, Shim, Mamo, Fosket, & Fishman, 2003; President’s Council on Bioethics, 2003). Medical interventions are reshaping norms of old age so that older persons (and their families) in the United States come to understand their bodies, lives, possibilities, and futures—including what constitutes the “normal” life span—in terms of their options about treatments that may or do extend life or enhance its quality. This is one powerful reason why it is so difficult for patients to refuse life-extending procedures even when they are very old. Life, health, illness, and death have become objects to be acted upon via the instrumental techniques that clinical medicine and the biological sciences offer (Rabinow, 2000; Webster, 2002). One’s own biological destiny is no longer fixed, immutable. Prevention, enhancement, and intervention are possible even into advanced age. We are made to embrace the idea that it is our responsibility to choose clinical intervention because biomedical technique has extended choice to every aspect of existence (Rose, 2001, p. 22), including the extension of ever longer lives.

We have shown through the examples of cardiac procedures, dialysis, and kidney transplant how medical choice operates, and how it is constrained and understood by clinicians as well as patients themselves in the context of the efforts of both to maintain and extend life. Empirical, ethnographic examination of medical practices that are are and are not actual treatment decisions reveals quandaries surrounding normalized treatments, the presumptive momentum of medical action, and the displacement of (deliberation over) life’s close by standard practices. Our examination also reveals the ways in which the human desire for hope and additional time is fueled by changing notions of old age in the context of routine life-prolonging treatments. The high stakes of no intervention, or of choosing not to intervene, coupled with the assumption that ever longer lives sustained by medical technique are expected and “normal,” underscores the reciprocity in the making of medical choice and old age in American society today. Developments in that relationship will continue to be an important site for gerontological research.

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