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Aged bodies and kinship matters: The ethical field of kidney transplant

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Abstract

The number of kidneys transplanted to people over age 70, both from living and cadaver donors, has increased steadily in the past two decades in the United States. Live kidney donation, on the rise for all age groups, opens up new dimensions of intergenerational relationship and medical responsibility when the transfer of organs is from younger to older people. There is little public knowledge or discussion of this phenomenon, in which the site of ethical judgment and activism about longevity and mortality is one's regard for the body of another and the substance of the body itself is ground for moral consideration about how kinship is "done." The clinic, patient, and patient's family together shape a bond between biological identity and human worth, a demand for an old age marked by somatic pliability and renewability, and a claim of responsibility that merges the "right to live" and "making live." Live kidney transplantation joins genetic, reproductive, and pharmacological forms of social participation as one more technique linking ethics to intervention and the understanding of the arc of human life to clinical opportunity and consumption. Significant in this example is the medicocultural scripting of transplant choice that becomes a high-stakes obligation in which the long-term impacts on generational relations cannot be foreseen.

Keywords

culture of medicine; life extension; intersubjectivity; biopolitics; life itself; kinship and kidney transplant; United States

Renal transplantation has emerged as the treatment of choice for medically suitable patients with end-stage renal disease. More than 60,000 patients await kidney transplantation and are listed on the United Network for Organ Sharing (UNOS) recipient registry. Live donor renal transplantation represents the most promising solution for closing the gap between organ supply and demand.

—*Journal of the American Medical Association*, 2005

How, then, might one begin to mark out the specificity of our contemporary biopolitics?

—Nikolas Rose, 2001

One of the effects of contemporary medicine, from a sociopolitical point of view, is to place death within a framework of ethical decision making that emphasizes the fight against specific mortal diseases and conditions (Bauman 1992). In the United States, more than in any other country, routine clinical practices often ignore the inevitability of the biological senescence in old age that eventually leads to death, and few moral, legal, or (so it often appears) financial barriers exist to halt interventions that prolong dying or treat end-stage disease as sustainable or even reversible. The activities that make up clinical life extension, like so many other medical practices, constitute a site for the governing of life and kinship and the emergence of new forms of social participation in which biological knowledge and identification are foregrounded. Our ethnographic example at this site is kidney transplantation for older adults, and we ask, what kind of subjectification emerges when longevity at older ages becomes an object of intervention and apparent choice?

We are concerned with how family and other relationships are implicated in a biopolitical field in which certain medical practices (along with their legitimating financial supports), the desire for and expectation of a longer life, changing ideas about “normal” old age, and family obligation become intertwined. The substance of the body, as ground for moral consideration, stands out as a dominant cultural feature in this example, especially for how kinship is “done.” Indeed, the materiality of the body and its relationship to notions of health has become an important frame for ethical judgments, generally (Rose 2001). We explore here the kinds of social obligations and, thus, moral order (Mauss 1967) at stake and in play when the age for transplant moves beyond 70 and, especially, when living donors come from the succeeding generation. The routineness of transplant procedures extends moral awareness and action to the body itself, we found, via the ever-present potentiality of being a donor or recipient.

This analysis is based on research conducted in 2003–04 in California on the consequences of life-extending medical technologies for older persons, their families, and an aging society. Our ongoing project interrogates the reciprocal effects of clinical medicine and late life, including what has become “normal” and “natural” about them.

The number of kidneys transplanted to people over age 65, from both live and cadaver donors, has increased steadily in the past two decades in the United States.¹ Transplants are routine in the seventh decade of life and sometimes are performed on individuals in their early eighties. Kidneys from cadaver donors over age 50 are sought and are made available to 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. Of the 15,135 kidneys transplanted in 2003 (for all age groups), 47 percent were from deceased donors and 53 percent were from living donors.² Of the 1,684 kidneys transplanted to people age 65 and over in 2003, 513 (nearly one-third) came from living donors, 295 of them from adult children of transplant recipients.³ The phenomenon of live kidney donation for older recipients opens up as yet unexplored dimensions of intergenerational relationships and medical responsibility.

¹According to the 2003 Annual Report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients (OPTN–SRTR), persons age 65 and over accounted for 11.1 percent of all kidney transplants in the United States in 2003. The percentage of transplants for older persons has increased steadily since 1988, when 2.4 percent of transplants went to persons age 65 and over (OPTN–SRTR 2003). The situation is similar in Europe; in 1999, 12.5 percent of all transplantations reported to the Eurotransplant registry were for persons over 65 (Schratzberger and Mayer 2003).

²Compare 1988, when the ratio of living to deceased donors for all age groups was 32 percent to 68 percent. By 2000, the ratio of living to deceased donors was fifty-fifty (OPTN–SRTR 2003).

³Although the actual number of kidney recipients in the United States age 65 and over has grown in the past two decades (from 213 in 1988 to 1,684 in 2003), the percentage of living donations to older persons has remained constant, at approximately 1 percent since 1989 (OPTN–SRTR 2003). For all age groups combined, the sources of living donation have shifted in the past decade. For example, spouse donations have increased over time, from 4 percent in 1993 to 11 percent in 2002. Adult child donors constituted 13 percent of donors in 1993 and 18 percent in 2002. Unrelated living donors increased from 2.4 percent in 1993 to 17.6 percent in 2002 (OPTN–SRTR 2003:table 2.9).

Ironically, even though biological relatedness is no longer a clinical imperative, given improved immunosuppressive techniques (the greatest increase in living donors has been among unrelated individuals [Mandal et al. 2003]), the nature of relatedness matters enormously, we found, in terms of one's sense of duty and responsibility for the health and longevity of a family member (or friend) with end-stage renal disease. Spouses, siblings, and adult children are usually the first to volunteer to donate when they learn of the need for medical intervention to save a life, and they represent the vast majority of living donors in the United States. Other relatives, friends, and acquaintances volunteer to donate as well.

In our own observational context, adult children (in their thirties, forties, and fifties) donate kidneys to their parents (currently, those who are in their sixties and seventies).⁴ Nephews and nieces, spouses, other relatives, and friends donate kidneys to older persons as well. Although donation to strangers and the global traffic in illegal organs have been reported in the media, heightening consciousness both about the desire and the need to give and receive and about the relative worth of life and health around the globe, there is little public knowledge or discussion of the transfer of organs from younger to older people.⁵ Yet the latter phenomenon is affecting more and more families (Dowd 2003; Grady 2001). In addition, the broadening of the eligibility criteria for legal kidney donation over the past three decades—to include not only healthy, relatively young cadavers and living family members but also older cadavers with diseases and nonrelated living individuals—marks a change in the credit–debt dimension of biomedical subject making. Along with this expansion in prospective and actual donor types, the recent, highly visible cases of apparently purely altruistic, philanthropic living kidney donation to strangers provide evidence of an expansion of moral claims of citizens on one another (see N. 5). An act that philosopher Hans Jonas (1970:16) termed “unnecessary” or “superfluous” in 1970, that is, “supererogatory,” has shifted, for a few pioneering individuals, at least, to a compelling requirement that is indicative of how the moral now may include deliberation about the uses of bodily substance.

Framing an ethic of care

At the site at which old age, end-stage disease, clinical medicine, and the contemporary, ubiquitous expectation for increased longevity meet (in the United States), we are aware of a new kind of ethical knowledge that is emerging through routine clinical treatment. We are not referring here to bioethics and the well-known parameters of that philosophically based discipline for clinical decision making in individual situations. Instead, we mean a diffuse ethical field, located throughout the social fabric and characterized by the difficulty, sometimes the perceived impossibility, of saying no—even in late life—to life-extending interventions. This ethical field is constituted by three features. First, the purported choices clinical medicine now provides to patients, prospective patients, their families, and their doctors regarding whether and when to employ life-extending procedures and whether and when to stop them are not really choices at all. Rather, choice is eclipsed by routine treatment. When procedures are shown to be effective at ever-older ages, they become routine and thus expected and desired by clinicians, patients, and families (Koenig 1988). When techniques become less invasive and associated with lower mortality risk, consumer demand for them and ethical pressure to make them available both increase. Ultimately, procedures that are seen to be relatively low risk quickly become standard practice. Treatment rationales and patterns are, thus, already scripted for patients and doctors, well before any actual “decision making” begins.

⁴To preserve the anonymity of clinics, health professionals, patients, and families, we do not name or describe our field sites, all of which are located in major medical centers in California.

⁵For reports on donations to strangers, see Parker 2004 and Strom 2003. See also *New York Times* 2004. For the worldwide traffic in illegal organs, see Rohter 2004. The movie *Dirty Pretty Things* (Frears 2002) also deals with the globalization of the illegal kidney market.

Second, the availability of interventions as therapeutic possibilities elicits hope for and expectations of cure, restoration, enhancement, and improved quality of life. In turn, the boundaries between medicine's focus on cure, prevention, and life prolongation are increasingly blurred in the desire to maximize life. These two features support and give form to the third: The nature of caregiving and love has changed so that expressions of care (both medical and familial), affection, and value are explicitly tied to clinical acts that either extend life in advanced age or allow "letting go." Families have always been implicated in medical care and its social ramifications, but the routine extension of older lives today via medical technique infuses familial obligation with judgments about the relative worth of clinical interventions, disabling chronic illness, suffering, and life itself.

The broadening of medicine's scope over the management of old age as well as illness per se (Arney and Bergen 1984; Kaufman 1994) reinforces and sustains these three features of the ethical field, which are mostly background to the daily activities of health care practitioners and patients. Yet they are the basis on which people come to understand the value of medical care and the uses of the body, their connections to one another, and the social worth of the oldest lives in society. Each practitioner, patient, and family must work out an ethic of care in the course of unfolding events, active and tacit decision making, and reflection. That ethic of care is rarely premeditated, autonomous, or deliberate. Rather, it emerges during social interaction and the unfolding of medical and interpersonal events. It is shaped by the structural features of medical specialties and the U.S. health care delivery system, the ways in which cultural understandings of kinship and community and epistemologies of clinical medicine influence one another (Franklin and McKinnon 2001:9), and, in the case of kidney transplantation, by the apparent mechanical ease with which body parts can be transferred from one person to another.

Expectations for ever-longer lives join expectations that routine medical treatment can extend a good life. For many, dying at age 71 or 81 is simply unacceptable because one can employ the tools of the clinic to restore health and stave off death. One patient's daughter spoke for others when she told us, "It's a shock to learn that a parent has a terminal illness, no matter what their age." (Although access to life-sustaining treatments, at every age, remains unequally delivered in the United States, the treatments themselves exist, and almost everyone knows this.) Things can be done, and the family is involved. Love is actualized often through the commitment to a longer life and by doing things to prolong life.

The possibility of giving away a part of the body becomes implicated both in the demonstration of care and love and in the ability and responsibility to prolong another life. The possibility of receiving the body part of another—the always already quality of this social fact—becomes part of the calculus by which the potential risk to another life and the sacrifice of another's bodily integrity are weighed in relation to the value of extending one's own life and improving one's own well-being. The expansion of moral consideration to include the possibility of the transfer of bodily substance is a cultural fact now, regardless of whether the acts of giving and receiving actually occur. To be confronted with end-stage kidney disease (of self or other) in a context in which transplantation and live donation are normalized is to engage the relationship between the body per se and the moral.

In this way, living donor transplantation joins the new reproductive technologies (Franklin 1997; Rapp 1999; Thompson 2001) in expanding the field of moral action to include proactive deliberation about the uses of one's own body and the uses of the bodies of others to achieve health and promote new or extended life. In the case of organ sharing, biology is not mobilized to configure kinship (Thompson 2001:175, following Schneider 1980), but rather, biology, as corporeal substance in the form of one's own body, becomes the central object in articulating moral claims on and relationships with another and in deciding what to do.

Intersubjectivity and the ethical field

Intersubjectivity is the quality, the precondition, that makes possible this ethical field. By *intersubjectivity*, we refer to the inextricable joining of self-knowledge, interpersonal relations, and social–ethical participation that constitutes, in large part today, the making of subjects. Together, embodiment and social emplacement shape people’s experiences of self and other, the parameters of identity and subjectivity, and the nature of relationships.⁶ Contemporary biomedicalization (Clarke et al. 2003) inflects bodily experience, self-making, and sociality with particular knowledge: about how the body is implicated in the ethical; for what becomes naturalized about the human, the family, and the lifespan; and for objectivizing the subject (Foucault 1983:208). Kaufman (2000,2003) has previously described a distinct form of discursive power and subject making in her ethnography of liminal forms of life and the clinical practices surrounding the mechanical ventilator, illustrating how “personhood,” the health of the body, and life itself are assessed, articulated, and negotiated through the intersubjective knowledge of players at the patient’s bedside. In the case of the life-extending medical practice we describe here—kidney transplantation in later life—the body, understood as transferable parts, becomes a central feature of intersubjective knowledge and relations. Organs can be variously “owned” and symbolically characterized, and they can be things, persons, self, and other, depending on one’s point of view (Sharp 1995,2001). Slippage occurs among these categories, and the breakdown of body and identity boundaries creates some angst in the transplant world, which has been described in detail (e.g., Fox and Swazey 1992;Lock 1996, 2002;Sharp 1995,2001). Yet the “good” of transferability (as illustrated in the first of this article’s epigraphs) is widely accepted and is evident in the growing demand for organs. That demand emerges from the broad expectation that end-stage kidney disease need not be fatal and from acceptance of kidney transplantation as a standard medical treatment for end-stage disease. A growing opportunity, thus, exists for family (and other) relationships to be ethically circumscribed via biological exchange.

Life-extending medical practices, in general, and kidney transplantation, in particular, present useful case studies for intersubjectivity and the expansion of moral consideration to bodily substance for two reasons. First, intersubjectivity includes somatic experience. Being-in-the-world is conditioned by the body–self and, thus, commitments, intimacies, and a naturalized, embodied (and, thus, nonreflexive) ethic flow from that experience (Csordas 1990, 1994; Kleinman 1997; Merleau-Ponty 1962). Second, participation in standard-of-care, life-extending medical treatments involves—indeed, cannot be separated from—the formation of self-responsibility and rights, on the one hand, and social connection and obligation, on the other hand. These two aspects of subject making are always co-constitutive. They are informed, more and more often, by clinical developments and imperatives.

On the self-responsibility side of the equation, older persons (and their families) in the United States come to understand their bodies, lives, possibilities, and futures—including what constitutes the “normal” lifespan—in terms of their options about medical interventions that may or that do extend life by postponing, altering, or ameliorating an end-stage condition. Nikolas Rose notes that by the late 20th century, knowledge of the living body “became intrinsically linked to interventions that transformed those living bodies” (2001:14). Life, health, illness, and death became objects to be acted on via the instrumental techniques that the biological sciences and clinical medicine offered. (See also Franklin 2000; Rabinow 1996, 2000.) One’s own biological destiny and that of one’s progeny are no longer fixed or

⁶The literature on subjectivity and intersubjectivity in the human sciences is rich and varied. Our thinking is grounded in the classic works of A. I. Halliwell, G. H. Mead, Maurice Merleau-Ponty, and Alfred Schutz and is influenced by recent work in the human sciences on embodiment, phenomenology, self-making, and social suffering and by ethnographic investigations of the social impacts of organ transplantation.

immutable. Prevention, enhancement, and intervention are possible, even into advanced age. One can choose to extend late life via medical action because biomedical technique has extended choice to every aspect of existence (Rose 2001:22), including the timing of death. One can choose not to intervene as well. Either choice is made within a cultural framework of increasing normalization of life-extending medical procedures.

The quest for health promotion and enhanced “quality of life” is ubiquitous in “advanced liberal” sectors of society (Rose 1996). The right (expressed in the United States largely by the middle class) to open-ended choice about life-extending medical treatments is marked by Medicare’s payment, in whole or in part, for many life-saving, life-extending procedures. Although Medicare is not available to everyone, and economic privilege is a strong determinant of medical choice, that right is starkly evident in the growing demand for kidney transplants by older persons, their doctors, and their families. The ethical demands on family, community, and society are, in part, obvious. In addition, existential knowledge of mortality is deconstructed through rationales and ever-emerging life strategies for “solving” and preventing the problems of discrete diseases, symptoms, and health hazards (Bauman 1992). An unprecedented mutability of life itself and old age, in particular, thus, sits in tension with the older truth of the predictable arc of human life (Cole 1992). People have become subjects responsible for authorizing (to the extent possible) their own health, longevity, and death.

On the other side of the equation, the nature of intimate family relations, intergenerational commitment, and one’s obligation to loved ones and to strangers in need, for instance, are affected more and more by biological knowledge and medical imperatives. Not only is the gaze of biomedical science and clinical medicine shaping the way people understand the self, the old body, aging, and interpersonal commitments but the multiple (and even contradictory) ways people understand aging, old age, and family matters are also changing clinical practices and the sense of responsibility toward the self and others that underlies those practices (Estes and Binney 1989; Kaufman et al. 2004). Clinical solutions and management strategies for aging bodies shape family and social dynamics and create new manifestations of discursive medicopolitical power. People’s claims on themselves and on one another are both visible and questionable in an unprecedented way: through the promises of the body enabled by an only partially articulated contract—about how bodily substance may be invoked in moral action—among the clinic, the patient, and the donor.

In the case of kidney transplantation, others are deeply implicated in sick patients’ self-responsibility to remain alive and to be as healthy as possible. Physicians and family, in their press to treat and desire and duty to “make live” (Foucault 1980), create an opening for a dual obligation for older persons—to be treated and to stay alive (not just to get well, as Talcott Parsons [1951, 1975] noted). That obligation, if taken up by the patient–consumer, is a pledge (as well as a burden) to others that one will follow the logic of medical intervention wherever it leads. Kidney transplantation at older ages is becoming ordinary, unremarkable, and so reflects and supports the unavoidable connection between judgments of value and biological existence and between health and social worth (Rose and Novas 2005). Its growing normalization (despite some people’s rejection of it) highlights, in addition, how “we make the ties that bind” (Laqueur 2000:91) between and among family members, generations, and strangers, according to the contingent intersections of biomedical expertise, the ubiquitous demands of consumer society on the self, and the culture of the contemporary health care delivery system. Even if potential donors and recipients decline to use their bodies in this way—that is, do not become actual donors and recipients—transplant medicine has created that potentiality, and decision making for everyone involved responds to that possibility. Our goal is to outline how the clinic, patient, and family together shape a particular kind of bond between biological identity and human worth, a demand for an old age marked by somatic pliability

and renewability, and a claim of responsibility that merges and organizes the (bodily) obligations of self and other.

The obligation of the gift

Marcel Mauss's explication (1967) of the "symmetrical and reciprocal" obligations of gift exchange—to offer and give, to receive and accept, and to repay—was effectively taken up by Renée Fox and Judith Swazey (1992, 2002) in their documentation of the impacts over nearly 40 years of organ transplantation on patients, families, medical practice, and U.S. society. The "tyranny of the gift" they describe—the imperative to offer and give and accept and receive the gift of an organ and the gift of a longer life, regardless of health or suffering, guilt or desire, and the painful "creditor-debtor vise" (Fox 1996:254; Siminoff and Chillag 1999) that may envelop givers, receivers, and families—has additional moral and social ramifications when the direction of organ transfer is from younger to older persons. That tyranny is marked by a sense among some recipients that this direction of transfer is unnatural and by a sense among some health professionals and others that this direction of transfer is inappropriate from the standpoint of medical goals and use of resources. Yet most patients with kidney disease want treatments that will enable them to live—and to feel as good as possible. We found, in addition, that many recipients feel obligated to live for their families, and donors feel duty bound to allow their parent (or older relative or friend) to continue living—and to facilitate that continued life.

Two socioclinical facts form the basis of this obligation. A transplant from a living donor has a comparatively high success rate and offers a patient a better prognosis than does the continuation of renal dialysis (Chkhotua et al. 2003; Mandal et al. 2003; Wolfe et al. 1999). And insatiable demand for transplants from older persons with kidney disease arises from and supports the growing normalization and naturalization of older kidney recipients. These realities put enormous pressure on family members, especially adult children, to donate (Fox and Swazey 1992, 2002), whether or not health professionals specifically urge, suggest, or opine against living donation. Not only must older persons continue to live but also younger persons must give. Not only are "routine" treatment patterns scripted but also old and young are deeply committed to one another, sometimes beyond deliberative choice. "It's just something you do, no question about it," we were told repeatedly by donors. Many prospective and actual donors view donation as simply "giving back" to a parent or other relative for all that he or she has done for them.⁷

The gift is "not a big deal," we were often told by donors after the fact, because medical technique has made kidney donation ordinary, easy, and of negligible risk to the donor. The gift is simply the best way to extend one life while, according to the medical discourse in the U.S. context, not diminishing or risking another (Davis 2004; Davis and Delmonico 2005). Yet it is, fundamentally, a sacrifice of the wholeness of the body and a nonreciprocal bargain. Among recipients there is much more ambivalence about it, as we show. Often, recipients' desire to refuse the gift is muted, masked, and overwhelmed by the routineness of accepting; the discomfort or refusal of dialysis; increasing serious illness; the willingness, enthusiasm, and persuasion of a donor; and the medical truth that a living donor will provide the best health outcome. These are powerful influences on what happens in the clinic.

Physicians shape the options for older patients and their families and encourage living donation when they stress the time sensitivity of the decision: Persons over 70 may become "ineligible"

⁷The ever-fraught gift relation is shaped with increasing regularity by poverty, coercion, and the global market in "bioavailable" kidney sellers and their needy and ready buyers (Cohen 2005). In the context of the illegal market, the "gift" is not the kidney but, for the seller, is the temporary reprieve from debt or economic ruin or the promise of economic gain. Often that "gift" is fraught with shame, chronic debility, and severe ostracism for the coerced donor-seller (Scheper-Hughes 2004).

for a transplant if they wait too long, that is, if they remain on the UNOS waiting list (four to six years at the time of this writing) for a cadaver organ. The older one is, the more precarious one's health may become in a few years, and, thus, the greater the urgency, both to be medically suitable for transplant surgery and for a transplant to be successful. The waiting time for a kidney from a cadaver donor over the age of 50 or 60 is not as long as the wait for a younger kidney, and there is virtually no waiting time for a kidney from a living donor. Moreover, little, if any, increased health risk, doctors point out, attaches to donating and then living with one kidney, even for decades (Davis 2004; Davis and Delmonico 2005). Patients and families quickly learn that their choice must take into consideration time and age, as the following comments demonstrate: "Realistically, you'll have to have someone donate you a kidney if you have a chance of getting one" (physician to a 77-year-old man with heart disease); and "I think getting you a kidney would be a great thing. But the sooner the better. It could be five to six years if you wait for a cadaver donor, especially because of your blood type" (physician to a 71-year-old woman).

Although health professionals we observed always indicate to patients that a kidney transplant carries some risk and that living with a transplant will not eliminate all health problems or the lifelong need for medications, they do stress that a transplant will free the person—as nothing else can—from the physical side effects and functional limitations of dialysis. If the patient is considered a good candidate for transplant by physicians, regardless of age, life extension and better quality of life are available (Wolfe et al. 1999). Medicare covers a great many of the costs of transplant medicine; Medicaid covers some costs as well. Transplantation is not a procedure only for the affluent.⁸ In large measure, then, if the patient has financial and other access to transplantation medicine, he or she decides whether to go forward with the procedure, and this fact marks a new gerontoethics.

Physician: It depends on how active you are and want to be. Transplant frees you. ... People who want to be active want the added years. It all depends on what you want. It's a personal choice.

Patient, age 71: Now that dialysis has started, I feel I'm in a holding pattern, a waiting pen. Before I started, I didn't realize I would think of it this way. I could never stay on it for years. I see transplant as my liberator, the light at the end of the tunnel.

Thus, one choice that is often presented to older patients and their families, or that emerges for them during the clinical encounter, is whether to accept a longer or shorter waiting period for a cadaver kidney—and possible death or greater infirmity while waiting—or to accept a living donor, "someone you know." Starting or remaining on dialysis is always an option, but health outcomes are better with a transplant (Segev et al. 2005; Wolfe et al. 1999), and so, when health professionals consider patients good candidates for a transplant, they encourage them to proceed. Also, in our experience, the vast majority of patients do not want to remain on dialysis if they can receive an organ. The shadow of death, the last and often unstated choice in these conversations, along with the negligible risk to living donors, hangs over the question of what to do.

The cultural context in which transplantation is routine and living donation is always already a possibility, coupled with growing numbers of living kidney donors for older recipients

⁸Most kidney transplant candidates (92.5 percent), regardless of age, are eligible for Medicare, which generally covers 80 percent of the cost of transplant surgery and 80 percent of the cost of antirejection medications for three years. In some cases, the costs of antirejection medications are covered for as long as needed. In some cases, Medicaid covers the costs of treatments for those ineligible for Medicare. And in some cases, Medicaid covers the 20 percent of the costs of surgery and medications that Medicare does not cover. Medicaid and veterans' benefits vary considerably from state to state. Donor services are completely covered by Medicare. See Medicare Rights Center n.d.; National Kidney Foundation n.d.; and U.S. Department of Health and Human Services n.d. In our observations, fixed-income and low-income individuals often received transplants. See also N.11.

(Mandal et al. 2003), adds a new dimension to kin obligation by forging a powerful, unprecedented connection between one's sense of uses of the body and one's idea of duty. Biomedical knowledge about the success of transplantation at older ages contributes to a dual truth about older bodies: They are a terrain for improvement and life extension and an objectification of the way family members, friends, acquaintances, and strangers may belong to one another (Edwards and Strathern 2000). The general success of kidney transplantation in later life opens a realm of possibility about future health and the self by telling people who they can be as recipients and donors (regardless of whether individuals actually choose to give or receive). That success both describes and paves the way toward a new manifestation of commitment (Franklin 2001; Kaufman et al. 2004). We suggest that the obligations surrounding gift giving and gift receiving, combined with medical technique, are contributing to a sense of a "natural" act, a "natural," longer lifespan, and a natural expression of love and belonging.

The site of ethical judgment and activism about longevity and mortality, in the case of kidney transplantation, is one's regard for the body of another, especially one's assessment of the role of the gift in that relationship. This decidedly corporeal feature of ethical relations is inextricably joined to the widespread quest for greater longevity and enhanced quality of life that are assumed to be available. Thus, the difficulty of saying no to life extension joins the tyranny of the gift in an unprecedented way.

Transplant subjects

We are interested in mapping a phenomenology and practice of responsibility and obligation in this ethical field, although we are well aware that our small-scale ethnography, to date, can only partially expose its characteristics.⁹ Among kidney recipients, prospective recipients, donors, and prospective donors, we tracked and elicited the following features of self-making and social connectedness: (1) whether one is willing to accept a living donor kidney, and if so, where one draws the line for acceptance—at spouse and siblings? children? coworkers? friends? strangers?; (2) the time it takes to offer, give, or accept a live donation or to be persuaded to accept; (3) the degree of aggressiveness in the search for a live donor; (4) the degree of willingness to begin renal dialysis, stay on dialysis for an unknown duration, or use dialysis as a short-term, stopgap measure; (5) the degree of urgency about asking, accepting, and offering; (6) the prioritizing of options: seeking a live donor first and considering cadaver donation as a last resort versus preferring to wait for a cadaver organ and turning to a live donor only when one's health deteriorates significantly; and (7) the worth and value of one's own life, relative age, and relative need vis-à-vis another. Each of these features that marks the transplant experience contributes to somatic self-fashioning and the biologization of intersubjectivity (Biehl et al. 2001:116). Moreover, these features both reflect and serve the clinical contribution to a certain kind of intersubjectivity—between older persons in need of and eligible for transplants and their willing and obligated potential and actual donors. That need and eligibility form the basis, the frame, for the work that prospective donors and recipients do when they engage the prospect of transplantation.

Although family relationships are central to kidney transplantation today, our conceptual aim here differs from explorations of what the "new kinship studies" counts as kin relatedness,

⁹Our small, opportunistic interview sample (as of December 31, 2004) of 33 kidney recipients between the ages of 70 and 81 (24 men and 9 women) approximately mirrors the U.S. national profile in terms of the ratio of living to cadaver organs transplanted: 19 to 15 (one person had two transplants from two live donors). We also interviewed 28 persons (age 70 to 80) who were being medically evaluated for a kidney transplant and spoke with 11 of their family members who had already offered to donate a kidney. Ethnically, our entire sample of recipients, donors, prospective recipients, and their potential donors reflects the broad ethnic diversity found in metropolitan California: African American, Euro-American, Chinese American, Japanese American, Hispanic, Filipino, Samoan, and immigrants from Afghanistan, China, Europe, the Philippines, and Vietnam.

especially those that analyze the social practices surrounding the new reproductive technologies (Carsten 2004; Franklin and McKinnon 2001). That is, potential kidney recipients and donors do not elaborate kin categories as do those engaged with reproductive medicine, and, thus, our goal is not to focus on the processes of conversion between the domains of the biological and social (Carsten 2001:50), or on how people deliberate what counts as a biological tie (Franklin 2001:302), or on how certain relationships are naturalized and made less ambiguous in the process of medical intervention (Thompson 2001:175).

Rather, our aim is to show how the social fact of the life-saving nature of living organ transfer is always already present when potential donors and potential recipients, along with others in their social world, express their moral claims on one another. We found that although those claims certainly invoke relatedness, especially, the emotional ties that accompany biological kin relations and those deemed to be “like” kin, our informants do not, specifically, elaborate kin categories *per se* to explain their participation in these procedures. It is precisely the “naturalness” of the kin (or “like-kin”) relationship—and, thus, the absence of needed elaboration—that justifies and normalizes consideration of the gift, whether one offers and gives (“It was just the thing to do, to donate—no question about it”; “This is the way it should be”) or not (“I will never accept a kidney from a living person; I would rather die than accept that responsibility”).

Our theme is the consequences of the normalization of kidney transplantation as a clinical-cultural practice. Moral claims are made and moral acts are called for because of the existence and significance of ties—whether biologically or socially defined or not—that are deemed to be in the service of a life-saving act. Those claims could not have been conceptualized before live kidney transplantation became “doable” and, in the case of older recipients, before the infirmities of old age, including end-stage kidney disease, were thought to be treatable. In this example, claims and then choices derive from standard-of-care-medical practice. The biomedical truth about the social worth and clinical efficacy of kidney transplantation operates as a cultural system (following Franklin 2001; Schneider 1980; Strathern 1992), shaping relationships in the form of an ethic of care. The work done by all players involved is to rationalize and emotionally come to terms with the prospects of offering and giving, accepting and receiving, and, importantly, deciding where one draws the line in networks of family (however defined), friends, and strangers and across relationships that are marked, in the case of relatedness, by protection, love, obligation, and indebtedness and, in the case of strangers or casual acquaintances, by apparent altruism and its acceptance.

The potentiality of offering, giving, accepting, and receiving a kidney puts pressure on parent-child, spousal, and other meaningful bonds. Within those bonds, offering is a sign of unconditional love, sacrifice, and the strength of the bond. For adult children, offering is a sign of thanks and payback for all the protection and nurturance a parent has given over a lifetime. Between spouses, offering reflects mutual care, support, and sacrifice and their acceptance. For recipients, taking the gift is a sign of thanks for love and of mutual obligation and an acknowledgment that the gift is appropriate.

A wealth of studies in science, technology, and medicine over the past decade illustrates the ways in which clinical truths and knowledge have profound interpersonal and intersubjective effects. In the case discussed here, clinical knowledge leads to an ordering, within the social worlds of both potential recipients and potential donors, of what kinds of relationships, if any, will be recognized as socially and emotionally eligible and appropriate for organ transfer. In the aggregate, kinship bonds rank the highest as we write this in 2005. But offers from friends, acquaintances, coworkers and, most recently, from strangers, and acceptance of those offers, appear to constitute a growing phenomenon in the United States for adult kidney transplant

(Nolan et al. 2004). The symbolic space (Carsten 2004:181) that kinship (however described) occupies in living organ donation may, in fact, be shrinking.

Recipients

The recipients and prospective recipients we spoke with articulated a broad range of ethical opinion about the need and urgency to ask for and accept an organ, the obligation not to ask and not to take, and the responsibility either to wait years for a cadaver donor or to quickly solicit one's own 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. Neither ethnicity, immigrant status, nor gender determined the ethics and practice of seeking or accepting an organ among our small but diverse sample of 33 kidney recipients and 28 prospective recipient interviewees.¹⁰

Patients articulated the ways in which they put into practice an ethic that balanced self-responsibility—for an extended life with family obligation and the pursuit of health—with selfishness and irresponsibility. Mostly, although not exclusively, as we illustrate below, the difficulty of saying no dominated the ethical field and charted the terms of engagement. Patients expressed a slippage between the expectation of life extension and the obligation to undertake it—they knew longer life was possible via medical intervention, but they did not always know, immediately, how to ethically rank their options for achieving longer life.

Some people want a kidney transplant as soon as (or before) they learn they have end-stage disease, and they line up prospective donors before their first visit to the transplant evaluation clinic and before talking with health professionals about transplantation. Some organize a list of potential donors to avoid starting dialysis and regardless of whether their physicians suggest or offer transplantation as a treatment. More than several patients said their 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 (live donor or cadaver) dawns slowly, over a period of weeks, months, or years after dialysis begins. Those in the latter group come to the transplant clinic for a workup and evaluation not necessarily because they feel ill or seek a transplant but, rather, because their primary care doctor or renal specialist suggests they do so. They are put on the waiting list for a cadaver donor. At that time, they may consider a living donor, even though some are ambivalent about a transplant.

For example, a woman who was 70 at the time of her cadaveric transplant, recalled,

From reading all the literature they gave me, I knew that family could be possible donors. ... Right away, my doctor set it up for testing the family, whoever was willing ... six people volunteered—even my mother who is 26 years older than I am. Only one sister matched, and she was too squeamish to go through with it. I had a few other friends over 60, 65, but I turned them down thinking they wouldn't really consider them at that age. But I stayed on the list a long time, until they found a cadaver donation. ... I felt at the time that I was getting old, and my life wasn't as important as some young person who needed the kidney. You would think that they needed it more than I did. And I was not even considering the transplant too seriously. Especially when I'd been on the list for over five years, and nothing had come of it, and most of my family had been eliminated or refused to do it. It just didn't seem like a very important possibility. Or, it just seemed too removed an idea. So I was just gettin' set to go ahead with dialysis for the rest of my life.

¹⁰Yet gender is implicated in the donor and prospective donor response to the need for a kidney. See N. 12.

The most passive actors are those who never entertain the possibility of a living donor, wait years, and eventually receive 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 at that time. I was quite hesitant about it, really. 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. And it was never clear to me where I stood on the list, either. 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.

Even the most passive, ambivalent patients—if they decide to remain on the waiting list—can receive a transplant simply by waiting for one (provided they continue to be medically eligible) because the clinical pathway will move in that direction. In those cases, more psychocultural work is required to reject a cadaveric kidney than to accept one because medical interventions to prolong life are routine, kidneys provide better health outcomes than long-term dialysis, patients want to live, and everyone around the patient (family, friends, and health professionals) supports transplantation as the appropriate, best intervention. In the first example above, the lack of volunteers among medically acceptable family members, coupled with the patient's assumption about who outside the family would be eligible, shaped her ambivalence about receiving a transplant at all. Over time, she conceived a hierarchy of worthiness based on a view of kidneys as scarce resources, and she decided that younger people are more deserving recipients than she. Transplantation as a solution to her health problem waned as a priority, yet she accepted a cadaveric kidney when her name came to the top of the waiting list.

People who actually make decisions of some kind in regard to seeking or accepting a kidney from a living donor express a range of ethical imperatives. From those who refused to accept a live donation we heard, for example,

The only thing they asked me was, did I have anyone in the family who was willing to donate a kidney for the transplant. And I flat out told them, no. 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, and I couldn't give him back the kidney. I even asked that question to others: Can I pass this kidney on after I pass on? Can they reuse it for somebody else? And they said no. ... I morally would not accept a live donor. 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.

I do not want a living donor. If something happened, I wouldn't like it, whether it's a relative or not. Let's face it. I'm not that young. I only have so much to go. I don't want to enjoy it at someone else's expense. I don't want to put someone else in jeopardy. I've got to go sometime. If I've got to go, I've got to go.

I got a cadaver transplant after a three-year wait. I would never ask my son. I had three years of peritoneal dialysis. I had to.

The most extreme version of this stance was articulated by a man with a wife and five children:

I had at least two people offer to donate me a kidney, if they were matches. I never had them go through the procedures because I took the initial position that I would never take a living kidney from anyone else. And if a cadaver kidney had not become available [after five years on hemodialysis] I would just—have gone through the regular dialysis until the end. ... And it was beginning to be a little more problematic

near the time I was called for the transplant ... if this fistula were to fail, I had come to the conclusion that I would just let it go and let nature take its course. I was just prepared to go ahead and expire.

Those who refused a living donation could not reconcile the potential risks of death or debility to a donor with the gift of a longer life for themselves, regardless of their relatedness to that prospective donor. In the shared calculus of these patients, the prospect of inflicting bodily harm on another loomed larger and weighed heavier than the desire or need to extend their own lives, and each took his or her chances on waiting for a cadaveric donation. Their judgments about the worth of their extended lives relative to the potentially compromised life of another were unequivocal, and they did not categorize the acceptability of the gift by ranking or defining kin and non-kin relationships.

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. One of the transplant nurses told me that that was nothing. She's seen people who have lined up a hundred prospective donors. You have to be proactive. You can't just sit around, or you'll die waiting.

When the team said, "We'll put you on the list for a cadaver transplant," my granddaughter brought up live donors and said, "We're ready." We had the forms filled out by seven people in 24 hours. I didn't consider anything else—I never went on dialysis.

My doctor said I would need a transplant when the creatinine got high enough. So I said, "How about if I line up some donors, or try to?" and he said, "It's kind of early for that. Let's wait awhile." When he decided it's time, I never hesitated. I knew I needed a kidney. I was real sick. ... With so much help from my wife, my kids—they're e-mailing everybody—I mean, it was a full court press to find donors. Talk about lucky. I never went on dialysis. I missed it by probably about a month. I had 25 volunteers to give me a kidney, and ten matched—they had type O blood. ... Of them, I had never met one, and one or two I knew casually, and the rest of them were close—two granddaughters, my daughter, and friends. Six women, four men. The hospital chose two, who scored the highest, and, amazingly, the two happened to be friends. And they were kinda arguing about who was gonna give me the kidney. They both wanted to do it. And I wasn't gonna get into that. The doctors made the decision. ... My secretary gave me a kidney. I just felt the luckiest guy in the world.

For these patients, the naturalness and good of transplantation as standard medical treatment muted or made irrelevant any deliberation about their own relative worthiness and what they understood as the relatively minimal potential negative health consequence to a donor. Although talk of sacrifice or risk to the donor sometimes emerged as an expression of a patient's moral calculus, those factors did not tip the balance away from a proactive search and then acceptance of the gift. Moreover, these patients had a great deal of family support in mobilizing potential donors from within and beyond kinship networks. The last of these three examples shows that kinship (however defined) is not necessarily a requirement for patients when they accept an offer, even if both kin and non-kin are medical matches. Solicitation of a living organ, regardless of how widely the patient casts the net or how the donor is categorized by the patient, occurs when patients, along with their support systems (which include health care professionals), understand transplantation first and foremost as a right and, along with donation, as ordinary medical practice.

Intermediate ethical positions occur as well, between outright refusal to accept a living donor organ and proactive solicitation of one. The ethical criteria for accepting a kidney from a living donor, and then who will be considered, are idiosyncratic and often change as the patient gets sicker, adjusts to the routine of dialysis, or receives an unanticipated offer of a kidney:

I have seven kids, but I don't think I want to ask one of my kids. If they volunteer, that's one thing. But I'm not going to ask. Who can take off from work? No one. [77-year-old man]

My sister knew I needed a kidney and I was tellin' her, "I sure wish somebody would come up with something." So my nephew called me out of the blue—I hadn't seen him since he was a young boy—and he said, "Aunty, I hear that you are sick." And I said, "Yes, I need a kidney." And he said, "I'm willing if you are." I said, "Are you serious?" and I explained how serious this was and how I wouldn't ask anyone to do this. I said, "Well, I don't know. You better think it over and call me up some other day." And he did just that, called me up another day. And they found out from the very first testing that we were compatible. ... And I said, "God, what if it doesn't work, because of my age, and I have to go back on dialysis?" But the doctor gave me a lot of confidence and said I had a strong heart. And I felt kinda funny, you know, about my nephew—suppose something happened to him? or something should happen to him more than me? And he was young. But, no. It was something he was gonna do. So here we are. I think it was meant to be. [woman who received a kidney transplant at age 79]

Thus, some patients will not ask for a kidney but will accept one offered by someone they know. They draw the moral line at the place where unprompted, insistent generosity meets a request that could seem coercive because of the significance of the bond. For them, an unsolicited and insistent offer of donation is evidence enough of genuine altruism, and they thankfully accept. Insistence and persistence on the part of the donor seems crucial to recipient judgments. Patients' own relative passivity in the situation allows their escape from a degree of moral culpability that could, perhaps, lead them to say no to the gift. Full moral agency is placed on the donor, instead.

For some, accepting a kidney from a younger family member was not objectionable per se. Rather, the issue at stake was the life circumstances of the one who offered. A woman who was on dialysis for five years before she received a cadaver kidney at age 70 said,

The doctors talked to me about a live donor, but there were only three that were a perfect match in my family—my oldest daughter and two grandchildren. My oldest daughter has the same problem I have, and eventually she's gonna go on dialysis too. The other one is her son, my oldest grandson. He was in the military. And when he found out about it, he went and got tested and he was a perfect match. And he came home to do it. I didn't know about it. And the [transplant clinic] coordinator called to tell me they had a match for me. My grandson was coming home to give me a kidney. That's how I found out. But she [the clinic coordinator] said, "I just got a call from his commanding officer and they're not clearing it. If he gives you a kidney, he's gonna be discharged. And your grandson says he doesn't care." I said to him, "No, you're not giving me a kidney. I'm not taking it. Because you're in the military, and if you give me one, they'll pull you out. I'm not at a life-threatening time now, so I'm not taking it. ... When I reach a life-threatening time, I'll put it in the newspaper. I would advertise. I'll put it out on the Internet, everywhere. So, until I reach that point, forget it."

People who will accept an organ from a living person ultimately establish a hierarchy of potential donors on the basis of varying combinations of the following characteristics:

biological relatedness, the strength and length of the tie between themselves and the prospective gift giver, the degree of enthusiasm or hesitation that person expresses about donation, and whether that prospective donor has responsibilities for other lives. That hierarchy reflects the construction of the ideal biosocial candidate for donation, as in the following scenarios: The son is running a business; he has four employees who rely on him. The daughter has two young children. But another daughter is not married, does not have children, and does not have the financial responsibilities of the son. She is the ideal candidate. Or, the daughter with two children believes she is the most physically fit member of the family. She offers and is adamant about it. Or, the children have their lives ahead of them. The patient would not accept from them because they may need their kidneys later on. But he or she will take a kidney from someone else, someone not as young as the children. One daughter donor explained, “My parents considered having my dad stay on dialysis, considered waiting for a cadaver, considered other potential donors who were nonfamily, at first. The reason is because family comes first, and you don’t want to put your kids at risk.” Kinship is invoked here as a moral category, and patients organize a system ranking those they will put at risk and whose commitment to them they will honor by acceptance. That ordering is made in a pragmatic context of who volunteers with the greatest persistence and who embodies the strongest dedication to a patient’s well-being. Thus, adult children arrive often, but not always, at the top of the list.

We often heard, at first, a negative injunction against asking one’s spouse, children, siblings, or other family to donate: “I’ll never take an organ from one of my children.” That negative stance reflected resignation to and acceptance of the nearness of the end of life—a long life—and, maybe, that the end was appropriate: “My wife wants to be my donor, but I don’t want to take from her. We’ve been married 50 years. I don’t want to bring her into this. This is end stage.” The daughter of a 75-year-old patient said, “He has a sister and me to donate, but he’s not accepting it. He’s very close to his sister and doesn’t want anything to hurt her. . . . He says he’s at the end of his age. But I say, ‘No, that’s not true, you’re not at the end of your life.’”

The initial refusal to consider one’s family member as a donor frequently gives way to acceptance weeks or months later because some patients feel extremely ill on dialysis or because they want the freedom and better health that a transplant promises:

The dialysis was killing me. I wanted to get off it as quickly as possible. I didn’t want to wait that long for a cadaver.

I was getting sicker and she kept offering.

She was saying, “Come on, Dad. My kidney isn’t getting any younger.”

Pressure on patients to accept a living donation is applied by prospective donors and by the structure of health care financing, which makes surgery and medications affordable for large numbers.¹¹ Whereas health professionals consider personal choice to be paramount for patients deciding whether to have a transplant, patients have relatively less choice about accepting a living donation if someone unequivocally offers because, together, enthusiastic prospective donors and the transplant team support the ethical field. Standard medical treatment that can and does treat aging and thwart dying, prospects of bodily freedom, better health and quality of life, and the love and care that are expressed through clinical intervention work in concert as compelling reasons to offer and accept. In the case of living kidney donation, the family

¹¹Medicare creates the possibility for transplant medicine in the United States, and there is no doubt that federal reimbursement regulations structure and inhabit the culture of the clinic as well as individual patient treatments and outcomes. Yet a discourse about moral economy—about the relationship between differential access to transplant and Medicare—is rarely articulated. We thank Lawrence Cohen for a discussion of this topic. A specific analysis of the financing of transplants and its impacts on the ethical field is beyond the scope of this article and is the topic of future research.

(and friends, acquaintances, and, most recently, strangers) serve as the agents of medicine and its goals (Biehl 2004).

Moreover, the responsibility to pursue greater health and longer life bleeds into the obligations people have for one another. The following form of reasoning stood out among those patients who ultimately accepted a kidney from a spouse or adult child: My family needs and wants me to live because it is possible for me to do so, and I want to live. Therefore, because I need to live, they (or some of them) will offer to donate a kidney for me, and (although it may not seem right) I must accept it. For example, one recipient recalled his clinic evaluation:

We were sitting there and she [the transplant coordinator] said, do you know anyone who would be a potential donor? And my wife, for years before, had said to me that she would be willing to donate a kidney, and I said, no, you're not gonna do that. I really didn't want her to donate. That's way too much to ask of anybody. I had told her, when it came up several times, that she's not going to do that. And this lady asked, "Is there anybody in the family?" And I said, no, they all have polycystic kidneys. And my wife said she wants to be the donor. And I said, no, I don't want you to be a donor. And they said, well, you don't really have anything to say about it. If she wants to be a donor, she can. And they did a workup and she was a match, very, very close. ... And then as things got worse and there was no possibility of being on the [cadaver waiting] list, I guess I kind of caved in and said, well, if the match is that good, and it will work, let's do that. I could have adamantly refused, but I didn't.

Another patient reported, "I went along with my daughter and with the doctors." And a third said,

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

The opportunity to continue living despite end-stage disease is handed to older patients (and their families) by contemporary clinical medicine. The expectation is widespread and growing that one can grow older—and that one can strive to grow older, despite chronic disease or even terminal disease—without feeling it, without an embodied sense of aging (Katz and Marshall 2003; President's Council on Bioethics 2003). "I wanted to get back to a normal life. Dialysis was just not acceptable. We are too active," said a 76-year-old man who rather easily accepted his daughter's kidney.

Saying yes to life-prolonging treatments also represents the obligation to remain alive. Several people told us they are enduring, seeking, or continuing treatment (either dialysis or transplantation) for the benefit of their children, some of whom are their prospective donors. The following statement from a 71-year-old woman describes how obligation overrode desire.

The huge decision was starting dialysis. That was a major decision, beginning dialysis at all. I knew it would impact my life. I did it for my son, for my family. I realized I needed to stay alive for my family. They needed me. I have an obligation to remain

here for them. If I had no family to persuade me to go forward with dialysis, I would not have done it. I would have chosen death instead.

The woman quoted earlier who received a kidney from her nephew had lost a daughter to cancer years before. Her sense of obligation to remain alive predated her need for a kidney. She said,

I was determined to take care of her five kids. I promised my daughter on her deathbed that I would take care of them. My husband and I, we told her that. That's why I went through this. . . . When the doctors told me that I was good enough to have a transplant, that I was still in good shape, then I knew that I could do it, that I could deal with it. And that's when I decided.

Overall, one can summarize recipients' ethic of care around two themes. First, recipient "choice," we found, is most clearly expressed in instances of refusal of a living rather than a cadaver donation. Those who refuse living donation do not limit their refusal exclusively to offers from family members and do not point, ultimately, to the bonds of kin relations as the reason for their refusal. Rather, they name unacceptable risk to all potential live donors or their own relative worthiness in terms of age and nearness of the end of a "natural" life or both as reasons to say no. Second, refusal often gives way to acceptance as health deteriorates or as donors persist in offering, because the stakes of life and relative health, the encouragement and guidance of the health care team and family, and the routine success of kidney transplantation, together, act as imperatives to go ahead with live donation, regardless of the moral stance of the recipient.

Donors

Donors' and prospective donors' side of the story of obligation, gift giving, choice, and no choice reflects their understandings of urgency and necessity in the life-and-death matter of kidney disease and its treatments. Their understandings include the expectation that mortality can be, and should be, pushed back into the hazy future. Thus, donors and prospective donors express a shared ethical clarity about their responsibility. A daughter stated, "There was no choice, no decision making. This was simply the thing to do—to donate a kidney. He needed one. I could save his life." A friend asserted, "I don't think of it as a great thing. I just think of it as a normal thing that people you know would do. . . . I just think it's a natural thing." Another daughter insisted, "Saving the life of my parent outweighed any other future consideration. There's nothing more important than family—it's just that simple."

We heard many variations on this theme, including the widely shared assessment that long-term dialysis was not a viable option: Dialysis is hopeless, a slow death, causes problems, and restricts life; donating a kidney is restorative, life giving, and freeing. Some donors came to this realization early in their parent's, spouse's, or friend's kidney disease. Others watched the deleterious effects of dialysis on the patient, for months or years, and then realized they could donate and so offered to do so—some offering more insistently until the patient said yes.¹²

Ethical clarity about the obligation to donate emerges from and is intimately linked to a sense of family solidarity, and adult children donors expressed a connection among family solidarity,

¹²Our opportunistic interview sample of donors included 17 women and four men, and it included the following relationships to recipients: six spouses (four wives and two husbands), three sisters, eight daughters, one son, one nephew, and two female friends. The three donors quoted in the text are all women. Within this small sample, wives offered and donated more often to husbands than husbands offered and donated to wives. Among siblings, women offered to donate to their parents before their brothers did, and they did so more easily, enthusiastically, and insistently. They were more adamant than their brothers that a parent accept their gift, and they expressed no reservations about giving. Our sample to date is too small to for us comment on the role gender plays in living donation. UNOS statistics show that men receive about one-third more kidneys (both cadaveric and living) than do women because more men have kidney disease. (In 2004, 9,574 men received kidney transplants; 6,428 women received kidneys. See OPTN-SRTR 2004.) The greater incidence of kidney disease in men also prevents them from becoming donors in equal numbers to women. This biomedical fact needs to be considered in an analysis of gender and the tyranny of the gift.

the ethics of the situation, and their sense of self: “We’re full-blooded Greek”; “We’re Italian–Spanish”; “We’re Dutch”; “We’re Japanese American”; “So you stick by one another. Family is the most important thing, and this was a matter of the family unit.” The ultimate importance of survival of the family unit was poignantly expressed in the unusual case of two sisters, each of whom donated a kidney, eight years apart, to their father:

When we came here from Denmark in the sixties, it was just the four of us. My sister and I were two and four years old. My dad had \$25 in his pocket and no job. That was the only time he was really scared. And he built his life, and we’re a very close-knit family. ... This journey is not about choice. It’s just something that you do. We weren’t forced to. ... We were willing to sacrifice our lives to maintain the integrity of the family unit.

Family suffering and perseverance were other themes in stories of donor and prospective donor obligation and solidarity. An adult child’s offer and gift are understood in relation to what a family has been through already. Expressions of family solidarity, what one does for another family member, do not stop when the parent becomes older and sick with kidney disease. Live donation allows family solidarity to be expressed through the gift of bodily substance. The strength and compelling nature of a tie to a parent can be enacted in the transfer of a part of the body across generations, thus, lending support and longevity to the entire family.

Among our donor and prospective-donor informants, a large range in the timing of offers reflected when, during the patient’s illness and medical workup, the donor realized she or he could, and should, make the offer. That timing is influenced by proactive patients, as illustrated above, but also by the independent dual realization, among family and friends, that they can offer and that their relationship to the patient “naturally” justifies their doing so. That realization may or may not be born of the urgency of the life-and-death stakes of the situation.

The timing of an offer to give is determined by physicians as well. Community doctors outside the transplant world were not uniform in their approach to living donation. Some suggested that the patient think about living donation, generally. Others mentioned a specific family member as an appropriate donor when end-stage kidney disease was diagnosed, when dialysis was imminent, or when dialysis had been underway for months. Other physicians never mentioned living donors at all, or they suggested that the patient remain on dialysis indefinitely, if the patient raised the subject of transplantation.

A daughter said, “We were watching him die. I could prevent his death. I wanted him around many more years. It was, in part, self-interest. I offered immediately, no doubts whatsoever in my mind about what to do. I volunteered before he, or anyone, raised the subject at all. I never was burdened or bothered by a sense of risk. There was no question in my mind.”

Other adult children explained,

When they told my mother she would have to start dialysis and go on the [cadaver] wait list I volunteered. They never mentioned it [live donation] at the clinic when she went for her evaluation. I could save her life, and she wouldn’t have to go on dialysis. My immediate reaction was to donate. “You’ve got four kids”—and we all volunteered, but I always assumed it would be me. I’m the healthiest. My mother was, frankly, relieved.

The moment he started dialysis, I offered. “Dad, you need a kidney.” It was the obvious thing to do. You don’t have something that your body needs to fully function, and it’s quite possible that I might have something that you can use. I’m the youngest and I think it [his reaction] was—“Nobody is cutting into my baby girl!” ... but after

nine months getting beaten up on dialysis, one day Dad said, “This is getting old.” I said, “Are you ready to get me tested?” And he said, “Yes, I think I’m ready.”

I could hear the desperation in my father’s voice when he started dialysis. All of a sudden, his active life was gone ... and to watch his deterioration was so hard. When I was being tested, he said, “Let me know as soon as they say it’s okay.” On the one hand, he didn’t want to push. On the other hand, he wanted it so bad. The dialysis was driving him nuts.

A 64-year-old woman who donated to her husband said,

My mother had one kidney. She had a kidney removed 42 years ago actually. And so I just got the idea one day that, well, if my mother can live with one kidney, well, I said, “I’ll give you [her husband] one kidney.” And he said, “I don’t know about that.” But I said, “It’s something we might think about.” He was in dialysis for two and a half, three years before I really thought about it. I said, “It’s getting ridiculous. I’ll just give you a kidney, if that’s what it takes.” He wasn’t receptive at first. He thought it was kind of risky. He was very worried about me. But I thought, people take risks every day. That’s when we started testing. ... If my family hadn’t had this experience, I don’t think it would ever have dawned on me. I probably never would have thought about it. Unless the doctor had said, “What about your wife?” Then I would have been willing. But I was the one who initiated it.

Future health risk to the self never weighed heavily (if it was considered at all) on the donors we interviewed. Many expressed their unequivocal trust in the transplant team and in the low probability of long-term negative effects on donors. They said they had no doubts about the outcome of surgery for themselves or the recipient.

We heard only one expression of ambivalence about volunteering to donate, and that one example was a direct response to the age and frailty of the prospective recipient. A woman who had already donated a kidney to her sister talked about the hesitation of her brother to donate to their mother:

My mom has a number of brothers and sisters, who ... we wanted them to step up to the plate. But there’s only so much—it’s a strange dynamic, where you don’t want to overtly pressure somebody. I think it’s hard for the person needing the transplant to sometimes ask for it. I know my brother, when he went through this process with my mom, and he got matched—it was a very hard decision for him, because in his mind, my mom had lots of complications. She’s already quite frail, and the issues—is the kidney gonna do her any good—he was weighing that factor. And he’s thinking, we have a family history of high blood pressure. What if he develops kidney disease later on? And he was getting married, and so, all those factors kind of played into it. ... It’s interesting. My mom didn’t want it from my brother. She felt like, if something happened to him, she would feel responsible. So, she actually declined it from him. She’s on the cadaver list.

In this case, the son apparently weighed the urgency of donation against the long-term health risk to himself. His mother apparently reasoned similarly, and she was possibly affected also by the son’s ambivalence and lack of enthusiasm about donation.

Like recipients, donors described how a hierarchy of donation within the family is established before medical testing for an adequate match begins. An ethic of appropriateness has to be worked out: “All of us [siblings] wanted to give to dad. We argued among ourselves about who should be tested first, who should get to donate. It was always a matter of which one of us gets to donate, not IF we should donate.”

A daughter who donated to her father said,

We all have different roles in the family. My brother's married and has two young children. And I think if the chips had really come down, he might have stepped forward. My sister is married. I'm single. I had nobody else to consider. I didn't have to consult anyone. So that's just the way it was. And so many people said, "Are your brother and sister getting tested?" And it was kind of like, well, I worked. I worked out. Why bother?

A 75-year-old man who donated to his 70-year-old wife said,

Naturally the kids said, "Take me." That was a given. They automatically offered. We didn't talk about it much. But we didn't want the kids. They're young, they have their own lives, and they may need their kidney later on. We both felt that if I was compatible, I would do it. And they were very happy with that. I was really worried, during the testing, that they would find something, or I would be too old, or I would have an abnormality in the other kidney, and I wouldn't be able to give. And it didn't happen and we were very pleased. And I'm sure the kids were relieved.

Personal health, age, time available, responsibility for others besides the prospective recipient, and sheer insistence all figure into the calculus of potential donors' own rankings among themselves. Although donors offer and give "without question," self-judgment about giving is intimately tied to perceptions of how one will be judged within the family, one's susceptibility to guilt in this regard, and the way the prospect, hope, ease, and routinization of transplantation shapes the value of (extended) life and ties it to social, especially familial, worth. Obligation and connectedness to others are mutually shaped by the ways in which reciprocity, duty, indebtedness, and love are enacted in giving and receiving a part of the body.

The shape of freedom

Enacting one's own freedom—through one's right, obligation, and commitment to health and long life—is a complex and demanding enterprise. Growing older without aging (Katz and Marshall 2003) is the form that freedom takes in the current era of routine life extension, an era that might well be characterized by the merging of the "right to live" and "making live" (Rabinow and Rose 2003). The case of kidney transplantation offers one empirical example of how that freedom is understood by prospective and actual donors, recipients, families, and health professionals and how it is organized in and by an aging society in which the biomedicalization of life is a dominant form of discursive power.

Death and choice about death are now thoroughly medicalized in the affluent sectors of the West, and the biopolitics of the "right to die" have been clearly (although narrowly) articulated in recent decades—control over the timing and means of death, symptom management, and humane rather than heroic intervention. Subjectification vis-à-vis death is marked by the right, responsibility, and freedom (if one is fortunate enough) to authorize the location, style, and timing of one's own end (Kaufman 2005). By comparison, although life itself and the stages of life (including the fetal) are also thoroughly medicalized, the freedom to "make live" in late life opens up a new truth about the relationship among intersubjectivity, obligation of and through the body, and the desire for extended life. That truth is constituted, first, by an ethical field in which life prolongation by medical means is a routine option and transplantation is wanted and encouraged; second, by the work done within that field to interpret one's own personal ethic of care regarding offering and giving and accepting and receiving; and, finally, by how recipients agree and acquiesce to the care and obligation expressed both by donors and the goals of transplant medicine. The impacts of the mandate to live on the transformation of the subject are revealed in a more diffuse, less homogeneous fashion than are the impacts of the "right to die."

From generation to generation?

That clinical technique contributes to moral sensibility is unquestionable (Brodwin 2000:10). Yet in his essay, “From Generation to Generation,” Thomas Laqueur (2000) emphasizes that the contemporary tensions surrounding the grounds of kinship connectedness, the meanings inherent in “flesh of my flesh,” did not arise recently with new (reproductive or any other) biotechnologies. Rather, he notes, modern medical interventions simply provide one contemporary site for age-old family relations and obligations to be expressed. Biomedical technique, in general, and live kidney donation, in particular, provide the most powerful logic and one persuasive method to demonstrate love and care. Live kidney transfer extends the boundaries of what can be given and received. It expands the necessary explanatory work (both for recipients and donors) to include assumptions about the naturalness of life extension and the routineness of the generational direction of the gift and to deemphasize the permanence of organ transfer and the finite character of this particular corporeal resource.

The biopolitics of relatedness emerged in the examples of our study subjects’ words. Everyone who engages the world of transplant medicine makes moves to include and exclude, to name and rank those who will be considered worthy of giving and receiving (Carsten 2004:180). Love, obligation, altruism, family solidarity, bodily risk, and assumptions about the naturalness of both mortality and transplantation play varying roles in individuals’ moral reckonings.

The nature of obligation—from generation to generation—was perhaps expressed most clearly by a 54-year-old woman who donated a kidney to her boss and friend, who, she noted, was like family. Although she thought about the impact her donation would have on her own daughter and her daughter’s children, she did not think about it for very long:

He said that he had a kidney problem and that he was gonna look for a donor because he didn’t want to be on dialysis. He gave me something to read, I think. But before then, I said yes. ... I’ve known X for a long, long time. We’re like family—it wasn’t a question. It was an easy decision. It prolongs the average recipient’s life by about 16 years, I was told. ... My daughter has one kidney. She had cancer when she was six years old and they took a kidney out. That was 30 years ago. So, I know a little bit about it. Knowing that no harm was going to come to me and knowing that, if down the line my daughter needed a kidney, she had some sort of backup, I think that’s what made it easy. I knew all of that. ... I discussed it with my daughter and my son—what I was gonna do; how they felt about it. My daughter was totally for it and she and I talked about it and I didn’t even have to say anything. She was the one who said, “Well, I have two sons, you know, if I need a kidney ...” And that made me even more comfortable.

This donor’s untroubled definitional move (Carsten 2004:180)—“we’re like family”—named the significance of her bond to the patient and justified her gift as appropriate and unquestionable, even to her daughter, who had only one kidney. This donor is not unique among those we spoke with in assuming that the transfer of her own kidney to another could instigate a “natural” obligation in younger generations to donate to older kin and like-kin in the future. That always potential obligation of the body of others does not appear troublesome.

“Natural” limits to life itself have been obscured. The denial of a biologically ordained, ultimately inevitable death has become naturalized (Featherstone and Hepworth 1998:156) both by clinical procedure and by an “ethics of normalcy” (Rose 2001:20) in which patients, families, and providers all participate. The old question that Laqueur draws attention to—what are one’s obligations across generations?—has not disappeared. As always, people must demonstrate the ways in which they care for the oldest members of their families and societies.

But, more than ever before, they are both being asked and demanding to share in those lives—in terms of bodily substance—through the medical procedures that are available.

Marilyn Strathern notes that medical interventions are also interventions “into ideas” (1992:5), and this is certainly true at the site of transplantation in later life. Just as the sonogram opened ways of seeing the fetus, its malformations, and the idea of prebirth intervention, just as surrogacy opened up the idea of motherhood and family, and just as cardiac surgery, the mechanical ventilator, and emergency CPR changed ways of thinking about the risk of death, so, too, the idea of organs moving from children to parents, between spouses, or between friends or strangers opens up the old issue of social and familial obligation to emerging biotechnical means of expression.

We are concerned with the forms of being a biomedical subject, and the forms of caring, that are developing now. Once the idea of live kidney donation, especially from a child to a parent, has been conceived, expressed, and made available to others (Strathern 1992:33), it becomes normalized as part of the ethical landscape for the practice of obligation and for proactively contributing to a certain kind of somatic and ethical future—for the self, the family, and subsequent generations. Live kidney transplant joins genetic, reproductive, and pharmacological forms of social participation as one more technique linking ethics to intervention, embodiment to possibilities for selfhood and family responsibility, and the understanding of the arc of human life to clinical opportunity and consumption. Significant in this example is the medicocultural scripting of transplant choice that becomes a high-stakes obligation in which the long-term impacts on generational relations cannot be foreseen.

Americans are routinely exhorted, and have been for some time now (Kristof 2004; President’s Council on Bioethics 2003), to think about gene therapy, human cloning, designer drugs, and so on, in terms of their dark potential to irrevocably alter “what it is to be human,” as though “society” were a decision-making entity that could, by some rational, discrete decree halt the development and uses of emerging biomedical techniques and thereby keep “what it is to be human” static, untainted, and, presumably, fully known. But the ways in which one is human are always changing and are always subject to change, regardless of scientific discovery and application. In an era of extreme physical violence, bodily suffering, and massive life disruption, it seems ironic to us that widespread societal rhetoric (in the United States, at least) about the “threat” to humanity’s essence centers on biomedical innovation and its promises, rather than on other sociopolitical activities. Although genetic research and its clinical applications have and will continue to have obvious implications for the nature of the human, many clinical practices, not based on contemporary genetic research, impact people’s relationship to life and its end and their responsibilities toward one another, practices that lie, it seems, under the radar of societal scrutiny. Routine kidney transplantation at older ages is simply one of them. Cardiac bypass surgery performed on persons over age 90, Medicare coverage (beginning in 2003) for the automatic implantable cardiac defibrillator (AICD), and tube feeding of the profoundly demented and permanently comatose are others. If and when these interventions are publicly noticed it is not because the procedures themselves are thought to alter what is natural about the body, the self, or the social but, rather, because of disagreement among patient, family, physician, medical institution, and the state over who has the right to authorize life or death—to let die and make live.

We have explored the space of routine medical treatment for one procedure to illustrate what is emerging in its wake. A price is paid for expectation and obligation invested in biomedical technique. We are only beginning to discover this price in terms of life extension in later life. As yet, the long-term ramifications, for the individual and for society, of donating kidneys to persons over age 70 are entirely unknown. We do not take a stand against this procedure and are aware that each of us could become donors or recipients—could welcome the opportunity

to offer and give or to accept and receive a kidney donation. We simply note that, in this example, people are all the subjects of a medicoethical experiment taking place on a broadening social scale. The desire and expectation for greater longevity, a given in affluent sectors of society that is driving a great deal of biomedical research and clinical intervention, is leading to greater biologization of people's moral commitments. The complex ethical field that continues to emerge, and the forms of embodiment, obligation, and somatic responsibility and connection that define us and that we are willing to accept are worth watching and documenting.

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