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Political Challenges to Biomedical Universalism: Kidney Failure among Egypt’s Poor

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Why do patients in need of kidney transplants in Egypt decline offers of kidney donation from their family members out of reluctance to cause them harm? Is it not universally the case that a living donor could live in complete health with a single remaining kidney? To address this conundrum, I discuss a case study from Egypt, in which patients reveal social, political, and environmental stresses on organ function that challenge the presumed universal efficacy and safety of kidney transplantation. I demonstrate that the biomedical position on the tolerable risks posed to the living donor is conditional and premised on particular social and historical contingencies that can be misaligned when applied in other contexts. Drawing on the work of Margaret Lock, I illustrate how analytical contributions of medical anthropologists can shed light on a political and public health impasse about how to legally regulate organ transplantation in Egypt.

**Keywords** Egypt, kidney failure, local biologies, organ transplant, political etiologies

In Egypt, a heated media debate over the ethics of organ donation stalled the passing of legislation to regulate such operations for more than three decades. The benefits of organ transplantation, elsewhere touted as a ‘life-saving miracle’ (Sharp 2006; Lock 2002), were less clear in Egypt, often overshadowed by horror stories in the newspapers about a thriving local black market for organs (al-Irqsusi 1998; Awad 2008; Fleishman and El-Hennawy 2008; Integrated Regional Information Networks 2006, 2008; McGrath 2009a). The vibrant trade in organs was largely understood to be both symptom and sign of Egypt’s larger entrenched problems of corruption and sharply stratified class inequalities. Organizations deeply saturated in religious discourse, such as the Muslim Brotherhood, sought to ameliorate political, economic, and what they saw as moral corruption throughout Egypt by calling for a ‘return’ to Islamic ethics that would restore human dignity. For some, such religious discourses could offer a way forward, improving medical practice in Egypt so that it more closely resembled the quality of medicine in resource-rich countries. For others, religious revivalism stood as an impediment to medical advancement as physicians and patients looked to the field of Islamic jurisprudence to weigh in on ethical decisions; not all Egyptians were convinced of its direct relevance. For still others,
religious discourses were mobilized to re-assess medical practices such as organ donation, and to highlight distinctions among ‘Western’ and ‘Islamic’ ethics, arguing that what is deemed ethical in the West is not necessarily the case under Islam.

Among this last group, a small number of physicians in Egypt were adamant that the procurement of organs from brain-dead patients was unethical because, they argued, the patients were not entirely dead. They formed a small lobby to pressure the media and legislators to ‘protect’ dying patients from potential murder under the guise of ‘cadaveric procurement.’ Many of their arguments resonated with mainstream Egyptian physicians who felt that the soul of a brain-dead patient was still ‘lingering,’ in contrast to North American medical practitioners who believed that the soul was gone, even if the body was biologically alive (Lock 2002; Sharp 2006). I discuss elsewhere why and how this small group of physicians in Egypt mobilized a civilizational discourse about ‘us’ versus ‘them,’ that effectively stalled the legislation of a national organ transplant program (Hamdy 2012, 2013). In this article, my aim is to demonstrate another outcome of this civilizational discourse: one that operated in the medical rather than legal sphere.

The rhetorical strategy of appealing to a specifically ‘Islamic’ ethics, in contradistinction to ‘Western’ norms in the field of transplantation, served to obscure medical precautions about the safety and efficacy of extracting kidneys from living donors.

CULTURAL DIFFERENCE?

Given the unavailability of cadaveric organs from brain-dead patients, Egyptian transplant doctors and patients in kidney failure were compelled to rely on living donors. Proponents of transplantation put forward the supposed ‘biomedical fact’ that a human being could live healthily with only one functioning kidney. They argued that no harm would be done to a living person were she to donate a kidney, and that the second kidney could be regarded as a ‘spare part’ or ‘reserve.’ During several years that I was in Egypt (2001–2004, 2008), I repeatedly encountered journalists, patients, and doctors who would appeal to these facts: people born with a single kidney and those who lose a kidney in accidents may never suffer symptoms of kidney disease. However, my research in dialysis clinics in Egypt’s northern provinces, among patients, their family members, and clinicians, showed that many people remained unconvinced, asserting that all body parts are necessary, and that the body in its wholeness is essential to a healthy life. Does such an assertion deny the ‘scientific fact’ about kidney function? Is it merely a ‘cultural’ ideology, similar to that which determines whether the soul of a brain-dead patient is lingering or gone?

Margaret Lock’s interventions in medical anthropology, premised on the notion that culture and medicine, and society and biology, cannot always so easily be separated (Lock 1993a, 1993b, 2001a, 2001b, 2002, 2010), are helpful to tease this out. Following Lock’s example, I demonstrate the importance of medical ethnography’s potential to: (1) challenge assumptions about the ‘universal’ (context-free) body, and (2) demonstrate social and historical contingencies in the production of biomedical knowledge. This task calls for highlighting the imbrication of social and biological processes, an approach that is necessary to understand why a presumably ‘life-saving’ and cost-effective treatment like kidney transplantation has remained unappealing for many patients in kidney failure, those who it would presumably benefit most. I join Lock’s and other scholars’ calls to pay attention to the body as the sedimentation of historically and
environmentally specific experiences (Lock 1993a, 1993b, 2010; Fausto-Sterling 2005, 2008; Gravlee 2009). In this case, attention to different bodily vulnerabilities enables us to scrutinize appeals to ‘cultural difference’ that can obscure underlying medical reasons for patients’ reluctance to pursue high-cost late-intervention treatments such as kidney transplantation.

THE SOCIAL LIVES OF MEDICAL FACTS

Surgeons in Egypt were the first in the Muslim Arab world to practice organ transplantation in 1976. Yet for 35 years, legislators in Egypt could not agree on how to provide a legal framework for transplantation, as they were divided over the legitimacy of a cadaveric program that relied on the body parts of patients deemed dead by neurological criteria. In the first decade of kidney transplantation in Egypt (1976–1986), the vast majority of kidneys were procured from living donors who were selling their kidneys. For some legislators, the question of the ‘black market’ in kidneys justified the need for legal regulation to reduce the dependence on poor sellers. For others, the seeming entrenchment of an illegal organ market proved that legislation could not adequately protect Egypt’s poor from selling their organs. The result was an impasse, and transplantation in Egypt continued without a legal framework (el-Katatney 2009).

While frequenting dialysis clinics in Egypt’s delta provinces, I met poor patients in kidney failure who were generally reluctant to consider transplantation. They often stated that the body ‘belonged to God,’ and that because God had created the body, it was not for a person to give, take, sell, or buy. They were especially reluctant to imagine a family member (unless it was a parent) in the position of organ donor, and feared the disruption of familial ties and the guilt that they would face for having received an unrepayable favor. Above all, dialysis patients in end-stage kidney failure worried about the harm that might befall a sibling, spouse, or adult child in the course of a kidney donation (Hamdy 2012). In many cases, patients expressed their concerns about the safety of the donor in religious terms, by asserting that the body, as a trust from God, was created in God’s perfect wisdom. This was an explicit rejection of the argument that the second kidney could be considered superfluous or ‘a spare part.’

Why was the medical argument that a person could live healthily ‘with as little as one-fourth a kidney’ unconvincing to so many patients and their family members? Although patients tended to assert that ‘the body belonged to God,’ in response to my questions, this did not explain why organ transplantation, but not other medical interventions like the ‘artificial kidney’ in the form of the hemodialysis machine, were of concern. One patient, Muna, who told me that she refused a possible kidney transplant because ‘the body belonged to God,’ explained that the only thing that kept her motivated to return to her thrice-weekly dialysis sessions was the hope that scientists would soon discover a way to clone her a new kidney via stem cells. Patients refused the notion of transplantation, but not out of a fatalistic rejection of human or technological intervention in ‘natural’ processes (Hamdy 2009). There was something specific to organ transplantation that was of-putting to patients, despite its promises to relieve them of their difficult lives on dialysis.

Journalists, politicians, legislators, and doctors wondered aloud what it was about ‘Egyptian culture’ that could explain this antipathy to organ transplantation. As one physician—who was also a consultant for [failed] proposals for Egypt’s nationalized organ transplant program—explained, ‘It is great to have an anthropologist study this problem! I am sure you will find that we Egyptians are attached to our dead, ever since the time of the Pharaohs and their mummies. This is the
core of the problem.” I am convinced that supposedly unchanging or unchangeable cultural practices around the dead do not explain Egyptian’s attitudes to organ and tissue donation. Rather, deep structural inequalities and corruption in public hospitals, punctuated by scandals reported in the media of body and body-part theft in public morgues, gave poor people little confidence that the bodies of their loved ones would be treated with the same respect or circumspection that more affluent people could afford in private facilities (Hamdy 2012).

Other physicians, nurses, and medical staff in hospitals told me that the Egyptian cultural trait of ‘atifiyya, or strong empathy, explained family members’ strong resistance to the tampering of bodies of their dead, and to bodies being cut open, disassembled and given over to hospital authorities. While some clinicians seemed moved by their fellow Egyptians’ ‘atifiyya, others were quick to lament Egyptian ‘backwardness’ that prevented organ donation. See, for example, the following plea from an eye doctor in 1989, frustrated by the low supply of donor corneas:

Some advanced countries in Europe and America have special documents like driver’s licenses for donating organs after death, but we unfortunately have not reached this sophisticated level of thought or culture, and that is why we need constant awareness campaigns for citizens to stop their wrong ideas.11

The heated and unresolved sociopolitical question about how best to show respect toward the dead came to overdetermine the parameters of the ethical debate on organ donation in Egypt, even in the context of donation from living donors.

As many doctors complained, the legislative proposals put before Parliament, rejected year after year, treated organ transplantation as a single legal reality. Yet ‘organ transplantation’ is an umbrella term describing very different practices, involving different procurement methods and addressing different diseases. Scandals related to the theft of eyeballs in the public morgue had a negative effect on public perception of living donation, and, in turn, stories of the exploitation of poor, living organ sellers tainted perceptions about donation of body parts after death. Meanwhile, state-backed messages from official religious scholars and physicians on public television and radio continued to attribute Egyptians’ reluctance to donate organs to ‘cultural backwardness.’12

This left very little space for patients to raise legitimate medical concerns about kidney donation. Next, I explain why it is inadequate to ask why Egyptian culture or Islam discourages patients to accept the biomedical risk posed to living kidney donors. To do so would leave unexamined the premises that transplantation is universally medically safe and efficacious, with biomedical, social, and financial benefits outweigh its costs and risks.13 But how and when did the benign nature of kidney extraction emerge as a biomedical fact?

**THE TRANSPLANT AS ‘VICTIM OF ITS OWN SUCCESS’**

In 1954, Joseph Murray and other pioneering surgeons and physicians embarked on the world’s first successful live donor human kidney transplant in Peter Bent Hospital in Boston (Calne 1999; Delmonico 2002; Barry and Murray 2006).14 The greatest medical challenge at the time was how to prevent the recipient’s immunological system from rejecting the foreign organ. The first successful transplant involved identical twins. The recipient’s genetically identical graft was not recognized as ‘foreign,’ and thus was not rejected, even without the use of immunosuppressive
drugs. In the 1960s, the development of immunosuppressive pharmaceuticals and a greater understanding of tissue and blood typing dramatically enhanced recipient survival rates, including for those whose kidneys originated from nongenetically related donors. Concurrently, surgeons experimented with the transplantation of organs from those whose brains had stopped functioning, usually due to major head trauma from automobile accidents. Preservation techniques to keep organs functioning outside the body were enhanced, enabling the successful cadaveric transplantation of kidneys harvested from patients across further distances (Lock 2002; Fox 1974; Lytton 2005).

In these early years, a bioethical dilemma emerged among medical transplant teams with respect to live donation, as saving the life of a person dying from end-stage kidney failure came at the expense of surgically intervening in a healthy asymptomatic donor. The Hippocratic maxim to ‘do no harm’ had to be violated to justify the surgical removal of a vital, functioning organ from a healthy donor. It was justified not from knowledge about human physiology or kidney function, but rather, from the notion of emotional well-being. One bioethicist put it this way:

Since the first kidney transplantation between identical twins was performed, both the medical profession and society at large have agreed that the use of organs from living donors is justified by the psychological benefit to the donor, who experiences the altruistic satisfaction of having assumed a risk in order to help another person. (Levinsky 2000, emphasis added)15

In the early years of kidney transplantation, as Renee Fox and Judith Swazey have documented (1974) medical and surgical pioneers in the United States were committed to study the ethical implications of these new procedures as the number of case studies slowly rose. Many surgeons had serious concerns about whether the recipients and living donors would survive (Lytton 2005; Delmonico 2002; Calne 1999). Yet organ transplantation had become ‘a victim of its own success’; the remarkable achievements and improvements in surgical outcome, with advances in immunological knowledge, tissue typing, and the development of immunosuppressive pharmaceuticals, dramatically widened the pool of patients who could be helped by transplantation (Sutaria and Adams 2010; Jamieson and Friend 2008; Sharp 2006). This sharply increased the demand for organs and tissues, and many of the earlier ethical dilemmas and cautionary stances were forgotten. Fox and Swazey (1974) documented their great disillusionment in transplantation in their follow-up book Spare Parts, after the field seemed to be overtaken by greed, prestige, and the technological pursuit to conquer mortality at all costs (Fox and Swazey 1992).

As transplantation became a successful, lucrative medical specialty, its techniques and technologies were increasingly naturalized in popular media depictions as a medical phenomenon whose success rested on physiological ‘truths’ such as the ability of organs to be ‘recycled’ in other bodies, and, in the case of living donors, the ability of the human body to compensate for an extracted kidney. If early transplant surgeons felt the need to limit living donors to those gaining ‘psychological benefit’ from the donation, a more pressing concern among transplant advocates a generation later was how to widen the supply of organs (Fox 1992; Fox 1974; Sharp 2006). In other words, the initial social, psychological, and ethical conditions that had led pioneering transplant teams to judge that the potential benefit of a transplant outweighed the risks were no longer at the forefront of transplant practice. It became a taken-for-granted
assumption, rather than something to be proven, that transplant surgery was a beneficial
intervention for patients experiencing organ failure. The stipulation that the donor benefit
psychologically—however problematically this might be ascertained—did not travel as far or
as wide as did transplant’s surgical techniques. Neither, necessarily, did the medical or surgical
conditions travel—such as the availability, soundness, and quality of the IV line, the catheter,
the anesthesia, the sterility of the surgical room, the techniques and tools for the extraction, the
amount of time the open wound is exposed to potential contaminants, or the amount and quality
of recovery time for donor.

The physical body of the donor on the operating table is another important factor in outcome:
the body is the sedimentation of a lifetime of personal and social habits, diets, environmental
exposure, and physical, intellectual, and emotional labor. In the United States, donors are
advised not to lift more than 20 pounds in the first four weeks of recovery, and to give up contact
sports after their surgeries. But organ donors or sellers may not have such luxuries of time or
resources; they may face high labor demands, daily physical assaults, vulnerability to dehy-
dration in hot climates, and dependence on irregularly accessible and poor-quality water. The
body under the surgeon’s knife is also the sedimentation of ‘social’ phenomena such as the per-
son’s emotional well-being, willingness to undergo the operation and attitude toward it—as well
as the emotional well-being of the surgeon (Gawande 2010; Shanafelt et al. 2010).

Delmonico’s analysis of his interview with Joseph Murray, the pioneering transplant surgeon
who carried out the first successful kidney transplant in 1954, is revealing:

In neither the first successful kidney transplant nor the brain death diagnosis did Dr. Murray (or his
colleagues) forecast its impact upon medical history. They did not anticipate either that clinical cir-
sumstance would become commonplace or so widely accepted. Thus, Dr. Murray was surprised to
learn that the annual number of live kidney donors in the United States had exceeded the number of
cadaver donors in 2001. He immediately expressed his concern about the probability of risk to the
live donor, with so many being performed. (Delmonico 2002:804)

The founders of transplant surgery envisioned the procedure to be extraordinary—one that
would be used for relatively rare and dire cases of patients near death. They proceeded with
caution, and as concerns arose about ethical and medical complications of using living donors,
it was largely agreed to be preferable to rely on cadaveric sources. They did not anticipate
a strong resistance worldwide to accepting brain-dead patients as ‘dead,’ particularly in countries
where the medical profession had less control over public bioethical debates (Lock 2002,
2012). Today, transplant medicine in the US has become routine, less a miraculous or heroic
feat that might be accorded ‘a state of exception.’ In the public imagination, ethical and medical
concerns about the health of living donors have been all but replaced with concerns about how to
increase organ availability (Sharp 2006; Fox and Swazey 1992).

In studying the production of scientific ‘facts,’ it is useful to recall the ‘symmetry principle’
developed by David Bloor (1991) and expanded upon, most notably, by Bruno Latour (2005).
This principle states that the same types of social, cultural, and political factors used to explain
the failure of certain scientific ideas should also be able to explain why other scientific ideas
succeed. In other words, we must employ the same analytical tools to study the social and
cultural factors that prevent particular notions from reaching the category of ‘knowledge’
(e.g., the inability of the new category ‘brain death’ to take hold in Egyptian society and medical
practice, or the reticence to accept the ‘negligible’ risk to an organ donor), as when studying how
such ideas gain acceptance or succeed (e.g., how the ideas of ‘brain death’ and organs as ‘spare parts’ were relatively easily accepted in North America).

The ‘symmetry principle’ was meant to correct the dominant trend among social scientists who were apt to demonstrate how social and cultural factors pollute, bias, or distort science, for example, through sexist or racist presumptions. While this is important work, the problem of demonstrating social distortion alone is that the sociology of science is thus reduced to the sociology of error (Bloor 1991). That is to say, ‘social’ causes are only seen to be that which distort or pollute knowledge, leaving ‘true science’ in its correct, pure form in an arena completely outside of social influences. This contributes to a teleological notion of scientific discovery, one that implies that nature will inevitably reveal itself to scientists, and that this process needs no social or historical explanation. However, medical anthropologists have long countered the assumption that ‘culture’ acts only as constraint to medical treatment, arguing instead that social cultural notions have shaped biomedicine, including the development of new medical technologies (e.g., Lock and Gordon 1988; Rapp 2000; Dumit 2003; Wendland 2010; Lock and Nguyen 2010).

THE SOCIAL LIVES OF KIDNEYS: POLITICAL ETIOLOGIES OF KIDNEY FAILURE

In Egypt, it was not only Cairo’s thriving black market or scandals about eye theft in the public morgue that led to a general antipathy toward organ transplantation. Patients, particularly among the poor, had good reason to distrust medical services. Particularly from the late 1970s, as greater resources, including the best medical talent, were poured into private hospitals, Egypt’s state expenditure on health remained at a low two percent of national gross domestic product, while out of pocket expenses, including among the poor, steadily increased (World Health Organization 2007; Fouad 2005; Shukrallah and Khalil 2012). Although all citizens under the law presumably have access to free health care, poor patients are usually examined and treated for nominal fees in public hospitals, where they are often mistreated and disproportionately serve as the teaching material for medical students, interns, and residents (Kamal 2004). Poor people are also at greater risk for contracting illnesses that would necessitate organ and tissue replacement, many presenting with undiagnosed hypertension, diabetes, and cardiovascular diseases, as well as infectious diseases resulting from erratic access to potable water, crowded conditions, exposure to toxins via unsafe food storage, labor practices, and iatrogenesis in public hospitals (Farag, Kari, and Sing 2012; Barsum 2002).

Instances of cardiovascular, kidney, and liver disease have increased throughout the country in the past three decades (Ibrahim 1995, 2012; Bassili et al. 2000). While epidemiologists
attribute increase in part to longer lifespan, the reduction of early mortality from infections, diet, the stresses of fast-paced modern life, and environmental toxicity all contribute to these trends (Ibrahim 2012; Galal 2002; Bassili 2000). Concerns about risks have been verified by toxicology and environmental epidemiology: industrial waste is the major source of pollution in Egypt; hundreds of industries discharge sewage-water directly into the Nile without proper treatment; and workers are often in direct contact with heavily toxic industrial materials (Sowers 2007; International POPs Elimination Project 2006). The poor quality of water, and its uneven supply, particularly in hot climates in which people are more susceptible to dehydration, can pose particular stresses on kidney function. This is exacerbated in a population with high rates of hypertension, diabetes, obesity, and exposure to endemic viruses such as hepatitis C and parasitic infections such as schistosomiasis.

Egyptian environmentalists have demonstrated that state management of water systems, including damming projects and the maintenance of irrigation canals, plays an important role in disease incidence (Taha, El-Mahmoudi, and El-Haddad 2004; AbdelShafy and Aly 2002; Lasheen 2008). The ambitious construction in 1970 of the Aswan High Dam to provide hydroelectricity throughout the nation also dramatically reduced water flow and the movement of the richly fertile Nile silt; farmers were thus compelled to depend on chemical fertilizers and pesticides that caused weed flourishing, blocked waterways, and caused stagnant water, the ideal habitat for the vector of schistosomiasis. Increased evapotranspiration further degraded water quality (Abdel-Shafy and Aly 2002:2; Sowers 2007). In an effort to respond to increased schistosomiasis infection, the Egyptian state in the 1970s launched a massive campaign in which public health officers went from door to door of villages up and down the Nile, dispensing tartar emetic injections as preventative therapy. Although it was yet to be discovered at the time, the virus hepatitis C survived the attempted sterilization of the needles via boiling, and the public health campaign inadvertently infected a large portion of the Egyptian population—somewhere between 10% and 30%—with hepatitis C (Frank et al. 2000; Strickland et al. 2002; McGrath 2009b; Sabry et al. 2005).

As patients in kidney failure spoke of worries about ‘the air we breathe, the water we drink, the food we eat,’ and as they learned of new diagnoses of kidney disease among neighbors or extended family members, it was less tenable to them that there were two categories of people: ‘sick’ (potential transplant recipients) and ‘healthy’ (potential kidney donors). As they saw it, many people faced various social, economic, environmental, and political stresses; of these some were more susceptible to falling gravely ill than others. As one research participant put it, ‘Why would I leave my brother with one kidney in the same environment that made me sick when I had two?’ Patients, when offered the possibility to accept a healthy family member ‘giving up’ a vital organ to alleviate their own suffering, voiced concerns about their responsibilities in mitigating the risks to their own bodies as well as to the bodies of their loved ones. Many physicians and even transplant surgeons shared these concerns.¹⁹

To suggest that kidney function is not a unitary, universal phenomenon would seem to contradict textbook depictions and popular portrayals of medical science. Yet for nephrologists, kidney function is clearly dependent on local environments. Medical clinicians face a range of human biological differences in their practice, as kidney function can be compromised differently by hypertension, diabetes, obesity, acute poisoning, a slower accumulation of toxicities, direct injury, parasitic or other infections, eclampsia in pregnancy, congenital anomalies, or auto-immune diseases. While working in Egypt’s dialysis clinics, I saw several young healthy
men who had fallen suddenly into kidney failure after having ingested the wrong dosage or type of medication, a problem all too common in the context of unregulated pharmaceutical dispensing and consumption. Many patients suffer symptoms of declining kidney function over an extended period of time; others experience the symptoms of acute kidney failure precipitously (Kierans 2005). Just as kidneys can be negatively affected by a wide range of factors, so too optimal kidney function is dependent on particular circumstances and environments. Human social practices that shape diet, reproductive behavior, physical exertion and activity level, and exposure to environmental contaminants, vary from one context to another, and accordingly, there is a wide variation in kidney function and in the etiology, prevalence, expression, and experience of kidney disease.

LOCAL BIOLOGIES AS ETHNOGRAPHIC METHOD

When proponents of organ transplantation argue that ‘there is no harm done to a living kidney donor,’ human biological difference and its social and environmental imbrication is erased by a façade of ‘universal biology’ and ‘universal biomedicine.’ Margaret Lock’s now classic work on menopause complicates this notion of a universal body. She compared the symptoms and experiences of menopause in Japan and North America to reveal that the supposedly ‘universally biological’ symptoms of menopause reported among North American women, such as uncomfortable hot flashes, mood changes, or constipation, are not equally experienced among Japanese women, who are more apt to experience aging through symptoms such as headaches and muscular stiffness in their shoulders and necks. Her work demonstrates that even phenomena such as menopause, which we tend to think of as universal, are expressions of socially contingent and historically specific practices, such as what and how we eat; when, how, and how often we move our bodies; and how we feel about and experience aging. Lock (1993) coined the term ‘local biologies’ to refer to this range of human physiological difference that can be explained by the entanglement of genetic, social, experiential, nutritional, and environmental factors.

Talking to poor patients and their family members in Egypt, I came to understand that they were the ones evoking the notion of ‘local biologies,’ as they pointed to the importance of the state’s (mis)management of infrastructure such as public water and waste systems, that can render vulnerable to illness particular segments of the population. Take, for example, Mahmoud, one of 58-year-old Mahdi’s six sons. Mahdi received dialysis at a public hospital where I conducted research in Tanta, and as he secured the painful bandages around the tube that linked his arm to the dialysis machine, he let his son, Mahmoud do the talking:

Kidney failure has really spread in the last few years. This could be because we are getting everything now from the outside—hormones in the food, pesticides in the fruits. These things are not natural; they are all poisons.

They talk about advances in science, but [transplantation] is really not a solution to the problem, because there aren’t [enough] kidneys available for all these people affected, and there are patients who have other problems. Like my father, he also has liver disease. And it could be that all his liver medicines are what caused his kidney failure. We are from the countryside. This [liver and kidney disease] is all from bilharzias [schistosomiasis] too; it gets into the organs and into the liver and affects the whole body. So getting a new kidney is not going to lengthen your life.
Neither Mahmoud, Mahdi, nor other patients and family members dismissed transplantation as a potentially successful treatment in toto; they knew that people with means in Egypt’s cities, and in wealthier countries in Western Europe and North America, could gain a new lease on life through a transplant. Rather than rejecting the medical intervention outright, they questioned whether all bodies would respond in the same way, arguing that bodies were constituted differently by different environments and lifestyles. In this case, they believed that while the extraction of a kidney from a living donor may be a tolerable risk for people in optimal health, it was not acceptable for those living in sociopolitical environments that pose physiological stresses on the kidneys and liver.  

Using ‘local biologies’ as an ethnographic method involves following the leads of patients’ own experiences. This might entail delving into toxicology (Hassan et al. 2006; Williams et al. 2004), water quality (Abdel-Shafy and Aly 2002, 2007; Lasheen et al. 2008), and epidemiology reports (Afifi 2000, 2001, 2003; Afifi and Abdel Karim 1996; Essamie et al. 1995; El-Agroudy et al. 2007; Gouda et al. 2011) or studying cases of medical iatrogenesis (treatment-induced illness; Ahmed et al. 2010; El-Sayed et al. 2000; Leila 2007) to tease out how particular environmental exposures shape bodily processes. It might also involve studying theological texts or works on Islamic jurisprudence to understand references about the body ‘belonging to God.’ In doing so, I am able to capture how patients live in and experience their bodies, and how they develop their own political etiologies. They link their vulnerability to kidney failure to larger social, political, and economic structures, while refuting corrupt medical facilities’ claims on their bodies by locating them firmly within God’s ownership (Hamdy 2008). In appealing to local biologies, these patients and family members point to how social, political, and economic history becomes embedded in people’s very physiology (Lock 1993a, 1993b, 2001, 2010; Fausto-Sterling 2005, 2008; Gravlee 2009; Gravlee and Sweet 2008; Fassin 2003, 2007). If we are to rely on Euro-American popular and medical discourse about there being ‘no harm’ posed to a healthy kidney donor, then there is good reason to question its relevance and applicability elsewhere. The factors determining the benefit and costs are always changing and context-dependent.

CULTURE AND BIOLOGY REVISITED

I began this article suspicious of the claim that ‘Egyptian culture’ alone could explain patients’ reluctance to accept the medical risk posed to living kidney donors. Lock has argued that anthropologists as a whole (particularly those not focusing on health or medicine) have been reluctant to take up questions of biological diversity for fear that human biological difference might be used as evidence of racist agendas (Lock and Nguyen 2010; see also Gravlee and Sweet 2008). We might consider the mid-1980s to mid-1990s as the climax of the anthropological inner turmoil over the ‘culture’ concept—a time when ‘culture’ was taken up as a racializing and essentializing gesture—in contrast to its original formulation. This had anthropologists calling for writing against it (Abu-Lughod 1991) or even to abandoning the concept altogether (Wright 1998). As Michel-Rolph Trouillot (2003) argued, the popular success of the culture concept was its theoretical demise; anthropologists lost control over the concept, and its use became a knee-jerk essentializing and even racializing way to explain behavior. Trouillot (2003) argued that one of the ways in which ‘culture’ had come to take on a troubling meaning was a result of its divorce from the political context in which it emerged; namely,
as a way to argue against racism in US society and politics. Franz Boas’ famous rebuttal to racist US discourses on immigrants demonstrated that the craniums of immigrants were not smaller because of ‘racial inferiority’ but because of adaptable and changing environmental impacts like diet and nutrition that would change in the subsequent US-born generation. In retrospect, while Boas succeeded in demonstrating that cranium size was not a constant factor, given its fluctuation and dependence on diet and environment, he left intact the notion that the white body (and cranium size) was the standard of measurement. Eventually, cultural anthropologists abandoned measuring human biological difference altogether, understanding culture as ‘super-organic’ and wholly unrelated from biological development, as defined by Boas’ student, Alfred Kroeber (1952 [1919]; Barkan 1992). Since Kroeber, cultural anthropologists have been reticent to address biological difference among people (Lock and Nguyen 2010; Fullwiley 2011; Gravlee and Sweet 2008; Barkan 1992). But medical anthropologists trouble this reticence by asking whether human biologies need to be compatible so that social claims can be recognized. Must Japanese women’s menopausal symptoms match those of North Americans to be acknowledged? Need Egyptian patients’ kidney function align with those of their North American counterparts for their concerns to be rendered legible?

Lock (2001) has argued that rather than ignore biological difference, we need to reassert that biological difference is not cause or justification of oppression, and that the Euro-American man need not be the universal standard for human biology. When we reconceptualize how cultures elaborate and make meaning of illness, we must simultaneously ask how cultural and historical processes also shape illnesses and treatments. Following Lock’s lead, in his analysis of AIDS in South Africa, Didier Fassin discards ‘culture’ as a stigmatizing way to explain the disproportionate HIV infection rate among blacks that so often invokes essentialist arguments about black sexual pathology (Fassin 2007). Fassin (2007) described the ways in which, as he put it, “bodies remember” the colonial violence of labor exploitation and the ways in which labor was extracted from male miners who were separated from their families and given ready access to alcohol, with its known disinhibiting effects, and prostitutes, conditions that quickened the spread of sexually-transmitted diseases. Women and children separated from male kin were more vulnerable to sexual violence and related exposure to HIV. Political conflicts, tuberculosis, and poor labor conditions further immunosuppressed laborers’ bodies such that the new virus spread faster (Fassin 2003, 2007).

Kidneys, too, tell stories of labor exploitation, toxicity, and political violence. High rates of kidney disease among Aboriginal Australian communities, for example, are partly explained by the abrupt changes of diet and lifestyle that many experienced with forced settlement and deterrioralization, putting them at nine times the risk, and in some communities up to fifteen times the risk, of end-stage kidney disease compared with nonindigenous Australians (Spencer et al. 1998; McDonald, Maguire, and Hoy 2003). Kidneys are also sensitive to histories of infections and scabies, which have been traced to the unsanitary conditions in which Aboriginal Australians were force-settled and schooled (Hoy et al. 1998). In Egypt, the poor patients with whom I worked were cogently aware that the mere ‘replacement’ of a body part was not the answer when their bodies as a whole, as well as the burdens upon their immediate and extended family members, were at stake.

As transplantation is increasingly globalized, initial ethical questions raised in the United States—including questions about whether it is justifiable to cut into and extract a vital organ from a healthy donor—are now overdetermined by ‘cultural difference’ as an explanatory framework. Medical anthropology poses a challenge to the assumption that ‘local people’ are those...
who react against biomedicine as science rather than enacting and producing it (Wendland 2010; Nguyen 2010). Here ‘culture’ ends up reifying the view that there is an unbridgeable gap between the modern and premodern, or the West and the rest—or however else this dichotomy might be renamed—the universal and the ‘local,’ the global North and the South. Locating ‘culture’ within biomedical science and demonstrating its dynamism, as well as its force in shaping bodies and illnesses, reasserts its critical edge as a rubric through which we can understand the logic, beliefs, health, and practices of a wide range of human societies.

By opening up the ‘black box’ of human physiology, medical anthropologists make crucial contributions to understanding that not all human bodies are everywhere the same; and that the biomedical insistence on a universal, culture-free body is itself a cultural artifact in need of explanation and analysis. Lock has long argued for an integrated perspective, one that entails an appreciation of humans as simultaneously physical, social, economic, and symbolic beings (Lock 1993; Scheper-Hughes and Lock 1987; Lock 2001; Lock and Nguyen 2010). But she has also been quick to note the formidable challenges of such a task, for we are “entrapped in our own Cartesian epistemological legacy” (Scheper-Hughes and Lock 1986:137), leaving us to resort to such fragmented concepts as the bio-social, the psycho-somatic, the psycho-social, or the somato-social. Despite the challenges that such an approach poses, we must continue to insist on grappling with the physicality of the human body and its formation by power—political, economic, environmental, and social forces—if we are to understand human life at all.

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NOTES

1. Since Egypt’s popular uprisings began on January 25, 2011, newspaper reports of organ theft or exploitation of poor organ sellers have increased.

2. For the official fatwa delivered by the Grand Mufti on the ethics of procuring organs from brain-dead patients, see Dar al itta’ (2007); for an analysis of Islamic and civil legal perspectives on organ donation in Egypt, see al-Bishri (2001).

3. I am not including patients’ perspectives on cadaveric kidney procurement, because, unlike in North America and Japan (Lock 2002), the issue of brain death has not been widely discussed among the Egyptian public; when I asked patients’ perspectives, most replied that they did not know about the issue. Egyptian physicians, however, were divided in opinion about whether the cessation of brain function signaled the complete death of the patient.

4. In long-term follow-up studies with living kidney donors, clinical researchers have demonstrated that their health levels were no lower than the average health levels of the US population (Gossmann et al. 2005; Fournier et al. 2012). However, because living donors must be in good overall health conditions when selected for, the average “American population” may not be the appropriate comparative group to assess the risks of living donation.

5. For two years, I conducted ethnographic research in the cities of Cairo, Tanta, and Mansoura, in private and public hospitals, dialysis wards, and state institutions. In addition to participant-observation of daily medical practice, medical conferences, religious lessons, and patients’ discussions in waiting rooms, I also formally interviewed more than
100 patients (those in need of kidneys or cornea grafts), 16 religious scholars, and more than 50 physicians (including nephrologists, internists, intensive care specialists, and ophthalmologists) to gain wider insight into the medical and social context in which the organ transplant debate took place. All subjects interviewed and observed gave their informed consent prior to inclusion in the study (Hamdy 2012).

6. It is easier to place the question about the status of the soul of a brain-dead patient in the realm of ‘culture’ rather than ‘science,’ as science explicitly does not take the soul to be a legitimate object of inquiry.

7. A successful kidney transplant can dramatically improve quality of life and is also much less expensive in the long run than a lifetime regimen of hemodialysis.

8. This is an Egyptian, God-centric expression of disapproval that the human body has come to be regarded as a mere exchangeable commodity. For medical anthropological critiques of the commodification of the body, see Sharp (2000) and Scheper-Hughes (2000). At the same time, many patients seemed to be wistful as they watched wealthier patients procure kidneys from donor-sellers. The common perception among clinicians and dialysis patients was that a typical seller-donor from whom they hoped to procure an organ was a plucky, young man who had ambitions about improving his economic prospects and who was able-bodied enough to believe that he could survive the extraction of a vital organ with minimal repercussions. For those who could bring themselves to consider buying an organ, many still dreaded the financial indebtedness that would result from liquidating assets or borrowing money to afford buying the organ from an unrelated seller. My fieldwork took place before the passing of legislation in 2010 that explicitly criminalized the buying and selling of organs; since this time, the law has been unevenly enforced.

9. Renée Fox and Judith Swazey (1974) memorably referred to the weight of the psychological burden and guilt associated with having received a donated kidney as ‘the tyranny of the gift.’

10. Most patients in kidney failure did not consider second-degree relatives as donors. For similarities, among African American patients also reluctant to consider family members as donors, see Gordon (2001).

11. This physician was quoted in Al-Wafd newspaper, July 12, 1989.

12. The trope of ‘cultural backwardness’ in public health discourse in Egypt is contrasted both with ‘correct’ (official) religious interpretation and with biomedical science (Hamdy 2005).

13. See Crowley-Matoka (2005) for an ethnographically based argument as to why the promises of ‘normal’ life post-transplant should be challenged; see also Crowley-Matoka and Lock (2006) for the uneven effects of transplantation throughout the globe.

14. The first cadaveric kidney transplant (rejected ten months later) was conducted in the United States in 1950, building on experiments with transplanting grafts of animals that had begun in the 1900s. See Manderson (2011).

15. This raises one of the many paradoxes and contradictions of biomedicine that can be seen in the realm of transplantation, analyzed by Lesley Sharp (2006). On the one hand, the justification for transplantation is premised on a strict division between an individual’s person and his or her body parts: the recipient is told that receiving another person’s organs will not alter his or her personality, or sense of self. And, as we saw in the case of brain-dead patients, US clinicians separate the ‘departed person’ from the mechanically assisted, biologically alive body. On the other hand, bodies and persons are thought to be intertwined: bereaved family members of brain-dead patients in North America are encouraged to think of their loved one as ‘living on’ through her body parts, in the lives of others. And in the case of the living donor, the ‘psychological benefit’ is said to (medically and bodily) compensate for the risks of surgical intervention. See also Manderson (2011) for how this works in the Australian context.

16. As Lock (2002) details, an ad hoc committee on brain death at Harvard in 1968 paved the way for a shift in clinicians’ reliance on cardiopulmonary criteria as the sole criteria for determining death, and allowed also, in rare cases, accepting neurological criteria to declare death. The neurological criteria apply only to an estimated one percent of people whose total brain function has irreversibly stopped while their remaining vital organs remain relatively intact. Most people who die in such circumstances are victims of automobile accidents or gunshot wounds to the head.

17. Among a minority of ethicists and transplant surgeons, however, has been a growing concern about the risks to living donors and the claims that donation is “perfectly safe.” See for example, Ross, Siegler, and Thistlethwaite (2007), a piece written by two ethicists and a transplant surgeon and others who call for the need for research on the long-term health effects of living kidney donation (Ellison et al. 2002; Ramcharan and Matas 2002).


19. There are legitimate bases of these fears, as demonstrated by early population-based epidemiological studies that have assessed risk factors among first-degree relatives of end-stage kidney disease patients (Gouda et al. 2011).
20. Japanese women also had significantly higher life expectancy, and lower rates of heart disease, osteoporosis, and breast cancer than US women (Lock 1993).

21. People who rely on organ sellers shift the medical risk to family member to a nonrelative; however in this article I refer to views of poor patients who did not pursue transplantation as a treatment.

22. Again, from within the Euro-American transplant community, several are now voicing concern about the long-term effects of living donation (Ross et al. 2007; Ellison et al. 2002).

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