

# Sacred Markets and Secular Ritual in the Organ Transplant Industry

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## **Abstract**

This paper examines how the procurement and exchange of human organs has come to be understood in the U.S. over the past 20 years. Drawing on a variety of qualitative sources, I show how advocates of organ transplantation articulated and refined a cultural account of donation that described and motivated organ donation. This account, which emerged from a range of alternatives, helped solve two problems: (i) harvesting organs introduced a utilitarian calculation at the time of death, and (ii) exchanging organs threatened to place a cash value on human life. The cultural account initially stressed the sacred aspects of the exchange. As structural pressure on the system has increased, so has the possibility of commodification. This is not a simple process of “marketization”, however. Instead, recent changes should be understood in the context of organizational efforts to (i) produce viable accounts of caring and altruism and (ii) manage the expressive dimensions of money in this kind of exchange system.

## INTRODUCTION

This paper examines cultural aspects of the growth of organ transplantation in the United States from the 1970s to the present. During this period, organ transplantation was transformed from an experimental therapy of last resort into a common medical procedure. As a consequence, demand for human organs has increased sharply and the number of people waiting for a transplant exceeds the number of available organs by a factor of about ten. A network of Organ Procurement Organizations (OPOs) has grown up to collect and distribute organs in the United States. Along with the government and the medical profession, these organizations have worked to increase the supply, both by collecting as many organs as possible, and by convincing more people to become organ donors. Organ procurement has the potential to be controversial. The reason for this, I argue, is that the effort to procure organs for transplant crosses two sacred social boundaries. It introduces a utilitarian calculation at the time of death; and it threatens to explicitly place a cash value on human life. The former problem concerns the dividing line between the sacred and the profane. The latter difficulty has to do with the role of money in the exchange of organs.

Sociological approaches to the spread of market exchange focus on the empirical question of how market exchange is institutionalized and legitimated, how it is adapted to particular circumstances, or how it is resisted. Other chapters in this volume show that distinctive cultures of exchange may develop in explicitly profit-driven contexts. Breugger and Knorr (this volume) demonstrate the emergence of norms of trading from the ground up in electronic currency markets. Schneper and Guillen (this volume) show that hostile takeovers are not simply a matter of market opportunity or corporate law, but depend also on the institutionalization of stock trading and the prevalence of cultural individualism. Currency trading and corporate raiding are innovations within an already well-entrenched set of economic institutions. But markets may also develop for goods already governed by some other principle of exchange. This is the problem of commodification.

Discussions of commodification are most often grounded in the philo-

sophical literature and their goal is to decide what is and is not commodifiable in general (Walzer 1983, Anderson 1993, Radin 1996). This chapter, by contrast, focuses on the cultural and organizational work involved in procuring and legitimately exchanging a potentially controversial good in practice. Standard debates about commodification tend to slough over this work, but it is central to understanding how a new, potentially threatening practice becomes morally acceptable — and indeed virtuous — over time. I argue that transplant advocates developed a specific cultural account of donation to resolve these problems. An account is a coherent body of reasons and evaluations that can be used to explain and legitimate some practice or activity (Wuthnow 1996, Scott and Lyman 1968). This account can be seen to emerge in the promotional materials and professional handbooks of OPOs, in books and memoirs about organ donation, and in the media coverage of donation issues. It amounts to a script, a set of “feeling rules” for the experience of organ donation, in Hochschild’s (1985) sense. I argue that this account is prescriptive rather than descriptive: it presents the ideal experience, what one ought to feel in these circumstances rather than what many people actually experience. Evidence for this comes from the fact that advocates of organ donation tried more than one approach before settling on the current rules; themes found in earlier sources are not found in later ones; the popular account focuses on atypical cases; and documentary and interview evidence shows a much wider spectrum of feeling about organ donation than the official account suggests. This process has, in turn, made it possible to seriously consider explicitly for-profit forms of exchange in human organs which were originally beyond the pale.

The paper is divided into three parts. First, I outline the theoretical approach. I show how Viviana Zelizer’s work on the life insurance industry provides the theoretical resources to approach this issue sociologically (Zelizer 1988). Second, I discuss the efforts of donor families and transplant professionals to make organ donation a worthwhile and appropriate act. I trace the development of their account of donation, and show how it has tended to rely on a particular set of arguments and stories. Third, I examine the growing importance of monetary incentives in organ procurement. I

show how practical systems of payment for organs recognize the expressive role of money. I argue that commodification is best understood as a carefully differentiated set of relationships rather than a simple yes-or-no choice.

## ORGAN DONATION AND COMMODIFICATION

Why focus on the transplant industry? Unlike more exotic human goods (for a survey see Andrews and Nelkin 2001), organs are widely exchanged in the United States through a well-regulated and carefully monitored system that can deliver them from donor to patient with great speed. Their exchange is much better institutionalized than more cutting-edge technologies, and so people have had an opportunity to develop practical responses to it and cultural accounts of it. This is important, as what is of interest here is how organ donation is presented and understood by those involved. This is not yet true of, say, cloning or gene therapy.

At the same time, it is only since 1980 that organ transplants have been possible on a wide scale (thanks to a new generation of immunosuppressive drugs), so the practice is still new compared to a few other human goods (such as blood) which have been around longer. Although the organ supply has grown in the past ten years, it has not kept pace with demand. The shortfall is severe, and produces many tragic, unusual or otherwise vivid cases — a sick child waits for a new heart, a famous sports player gets a new liver, the family of a brain-dead accident victim refuses consent to donate, and so on. One response to the shortfall is to introduce a financial incentive for organs, creating a production market for them. But commercial traffic in organs seems disturbing, even obscene, to many. An altruistic system seems the only justifiable solution. The result has been a classic commodification debate.

How should we think about this issue? With a few notable exceptions, (Fox and Swazey 1974, Simmons et al. 1977, Fox and Swazey 1992), sociologists have not paid much attention to organ transplants. But we do know a good deal about how people think and talk about their own altruism (Wuthnow 1991, 1995), how they use money to express social ties (Zelizer 1994),

and how people manage money in personal relationships (Nelson 1998). Research in this area suggests that the problem of commodification is not about the encroachment of the market on some untouched region of society. Rather, it is about the ways in which people account for their own actions and the place of money in their lives.

Take life insurance. As documented by Zelizer (1988, 1979), life insurance was a controversial product in its early days, and is a good example of moral debate about commodification. Though promoted by legislatures, life insurance companies were unsuccessful in the first half of the 19th century. Americans did not want to buy any. This changed between 1840 and 1860, and insurance companies grew rapidly. By the late 19th century, life insurance was commonplace, and earlier controversy about it had abated.

Life insurance threatened to assess a person's life in financial terms. Compared to other goods up for commodification, it seems quite harmless. We would say that, unlike slavery for example, it doesn't *really* put a cash value on you as a person. But many 19th century commentators felt it was just that: it was "merchandising in human life," and "turning a very solemn thing into a mere commercial transaction" (quoted in Zelizer 1988, 291). Americans did not want to buy life insurance because they did not want to put a price on their heads.

There is also a close relationship between life insurance and death. The policy yielded its reward when the owner died, so buying life insurance meant tempting fate. Life insurers were aware of "the mysterious connection between insuring life and losing life," as customers confessed that they feared taking out a policy would hasten their deaths (Zelizer 1988, 292). Such views are typical of the many traditional, magical strategies used to ward off death and illness (for example, not mentioning death by name, not speaking the name of an illness for fear of contracting it, and so on). Social processes or professions related to death are usually subject to magic rituals of this kind. With life insurance, the presence of money meant further ritual effort. The result was interesting. Death was not profaned by money. Rather, money could be transmuted into an offering of sorts, and life insurance made possible a proper, respectable — even lavish — funeral. Thus,

[t]he dual relationship between money and death — actual as well as symbolic — is essential to the understanding of the development of life insurance. Sacreligious because it equated cash with life, life insurance became on the the other hand a legitimate vehicle for the symbolic use of money at the time of death (Zelizer 1988, 293-4).

In short, Zelizer argues that, insurers had to reconcile the demands of business for profit with the sacred aspects of the good in question. One did not simply triumph over the other. Rather, contradictions were overcome through “the transformation of monetary evaluations of death into a ritual . . . life insurance assumed the role of a secular ritual that emphasized remembrance through money.”

The correspondence between life insurance and organ transplantation is not perfect, of course, and the comparison should not be drawn too strongly. The goods are differ, as do the structure of payment and the list of potential beneficiaries. The life insurance industry created a tradeable commodity in a controversial area, but the market for insurance did not threaten an already-existing system of gift exchange. Further differences could easily be enumerated. Yet the comparison remains worthwhile, because exchange in transplant organs crosses similar boundaries to those Zelizer identifies for life insurance, and the framework she uses to approach the insurance case can fruitfully be applied to transplantation.

Organ procurement is done with care, but it could hardly be more invasive. It is difficult to make this procedure acceptable to people. In circumstances where there is a great shortage of organs — and the market seems like a possible solution to this problem — these difficulties are exacerbated. In the next section, I trace the production and propagation of a cultural account of organ procurement that morally justifies this procedure and tries to motivate people to participate in it.

## BUILDING AN ACCOUNT OF ORGAN DONATION

Organ donation is a novel medical procedure that, in most cases, demands a remarkable sacrifice from someone who has just lost a close relative, usually through some violent accident. It is not obvious that people should consent to donation under these circumstances. Ruth Richardson has argued that the closest historical analog to organ harvesting is the dissection of the dead for anatomical study: “Both depend upon an accessible supply of dead bodies. Each damages the dead body for the sake of what is generally seen as a greater good. Both processes break cultural taboos” (Richardson 1996, 68). Many religious doctrines pose potential stumbling blocks for donation. Some societies — Japan is the most prominent example — have opposed organ donation and transplants (Lock 1996). Even when generally accepted, organ procurement can spark moral controversy, as Hogle’s (1999) study of organ procurement in Germany shows.

I argue that we can trace how organ donation has been rationalized by OPOs and made meaningful by donor families. Zelizer describes three ways in which secular rituals developed around life insurance, in each case through the efforts of insurance providers and religious activists. First, it became a way for the bereaved to come to terms with the death of a loved one. Second, it became a moral act with religious significance. Third, it became a way to guarantee one’s memory after death, and thus a kind of immortality. Her categories can be applied to the present case. We find a similar cultural account and body of secular ritual emerging in the contemporary world of transplant organs.

To make my argument, I rely on three sources of data. First, I examined promotional material, official reports, policy statements and other discussion papers originating with OPOs or their co-ordinating agency, the United Network for Organ Sharing (UNOS). Second, I collected a comprehensive sample of book-length journalistic accounts or personal memoirs of organ donation published between 1980 and 1999. These books began to appear with increasing frequency in the 1980s. The official sources reflect the interests of the OPOs in increasing the organ supply, and represent their best



efforts at convincing potential donors that giving organs is a worthwhile thing.<sup>1</sup> Like the advocates of life insurance, they lay out arguments in favor of a practice that trespasses on questions of life and death in a disturbing way. The stories told in the popular books add narrative detail and emotional depth to these policy arguments. I argue that they act as a cultural resource, a way of familiarizing the public with the rules and ideals of this new practice. They publicize the experiences of those affected, providing rich, personalized, narratives about donation to all those involved. (References to these books can be found in the bibliography.) Third, I sampled the *New York Times* (via the Lexis-Nexis database) for all stories appearing between January 1st 1980 and December 31st 1999 that had the words “organ” and “donor” or “transplant” in the headline or lead paragraph. The initial search yielded 1012 news items for the whole period. After checking each story, 14 were eliminated as irrelevant leaving 998 items. Figure 1 shows the trend in coverage over the 20 year period sampled. The median number of stories per year is 50, with a minimum of 9 (in 1980) and a maximum of 86 (in 1999). Figure 1 shows the number of news items each year over the period sampled.

[FIGURE 1 ABOUT HERE]

### *A way to cope with bereavement*

Between 1830 and 1870, life insurance companies justified their product as a way of coming to terms with death. Far more than a financial safety blanket, life insurance was a consolation “next to that of religion itself” (quoted in

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<sup>1</sup>I do not mean to suggest that there is no debate amongst transplant professionals about what the best procurement strategies are. There are three alternatives: (i) Proposals to increase the donor pool by pursuing “non-heart-beating” donors more aggressively. (ii) Proposals to eliminate refusals by curtailing the rights of donors or (especially) their families to veto harvesting, or (iii) Proposals to introduce some monetary reward. Proposals of type (i) are gaining support in the profession, but threaten to undermine years of effort to educate the public about brain death. Type (ii) proposals tend not to have much support. I deal with type (iii) below. I also show that, at different times, there has been some uncertainty amongst OPOs about which altruistic strategies would work best. At present in the U.S., there is essentially no organized lobby that opposes organ transplants.

Zelizer 1988, 294). In the first issue of the *American Life Assurance Magazine* (1860), Morris Franklin asserted that life insurance could “alleviate the pangs of the bereaved, cheer the heart of the widow and dry the orphan’s tears.”

The florid prose style is no longer in fashion, but UNOS makes the same argument about becoming an organ donor:

At the time of your death, your family will be asked about organ donation. Sharing your decision with your family will spare them the added burden of having to guess your wishes at a difficult time . . . Carrying out your wish to save other lives can provide your family with great comfort in their time of grief. (United Network for Organ Sharing 1999).

In most cases, a donor becomes available for organ procurement through violent or accidental death.<sup>2</sup> The victims are often young, and their deaths are unexpected and meaningless. OPOs stress how the organ donation can help a family make sense of such a tragedy, to give some meaning to it. A number of journalistic and first-hand accounts from the donor family side have been published: Pekkanen (1986), Gutkind (1990), Schomaker (1995) and Green (1997) are examples. In addition to books like this, volunteer donor organizations encourage donor families to tell their stories. It has become common for these to be available on-line. For example, the Transweb Memorial (available at <http://www.transweb.org/>) has memorials for about sixty donors.

These testimonies movingly articulate the grief of the families involved and relate their responses to the procurement request. They generally confirm the claims of the OPOs about the benefits of donation. Donating organs can invest an otherwise senseless death with some meaning. Alice Sanders is a typical example. She tells how she consented to have her husband’s organs donated:

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<sup>2</sup>For example, motor vehicle accidents caused the death of 26% of cadaveric donors in 1997. Homicide or suicide victims accounted for a further 15%.

A day of sorrow for us turned into a very bright day for several families, as we were able to donate kidneys and the liver. My thought several times that day was how excited those recipients must have been when their pagers went off, knowing that they were getting a “second chance.” (Sanders 1999).

In *The Nicholas Effect*, Reg Green describes how his seven year-old son Nicholas was killed during a botched car-jacking while the family were on holiday in Italy (Green 1997). They consented to donate their child’s organs to the Italian procurement system. Seven Italians received Nicholas’s organs. The story understandably provoked a tremendous response in Italy (resulting amongst other things in a jump in the donation rate there) and the book describes Green’s feelings about what came of his son’s death.

This case brings out some subtle aspects of the gift relationship. Green’s case provoked so much sympathy in Italy because he had this terrible thing happen while he was a visitor there. If you agreed when you read that the Italian response was “understandable” then you shared an assumption about a group’s obligations to guests. It seems fair to say that Italian reaction would not have been as strong if the victim had been a local resident. This is odd, because we normally care more for those closer to us. But group identity can produce feelings of responsibility, and even shame, in this way. These feelings were amplified when Green acted generously toward the group.

As Mauss long ago recognized, gift-giving creates a bond of solidarity, as the giver shares what he has; but also a relationship of superiority, as he creates a debt which must be repaid (Godelier 1999, 12). Italy was doubly in debt to Green. The strong popular reaction can be seen as an expression of the feeling that the wrong done to him as a guest, combined with his selfless reaction to it, created a debt that was almost impossible to discharge. The country was shamed by a stranger’s unwarranted generosity.

The feelings expressed in the on-line memorials are much more varied than those in the published books. Not all articulate the benefits of donation as well as Alice Sanders, or manage to find meaning in the way the Green

family did. Often they consist of a short note or poem expressing grief, nothing more. Sometimes, writers express resentment at the anonymity of the donation procedure:

Oh, recipients where are you, you who live because our beloved donor has died? Can you not acknowledge your appreciation to your anonymous donor's beloved family? After all, the organ didn't come from a donor, it came from my beloved brother.<sup>3</sup>

We have no comparable literature describing the experiences of those who refuse consent to donate. We do know that a substantial percentage of donation requests are refused — perhaps as high as 50% (Gortmaker 1998) — indicating that the OPOs need to work hard to make donation a standard choice.

The Transweb memorials are public, but they are much less refined than the books on the subject. Though the books recount great suffering on the part of the families involved, they are positive and life-affirming. They can be read as “feeling rules” in Hochschild’s (1985) sense. They lay out a template for those who might be put in the same situation, following the story through to its moment of closure and acceptance. The narrative structure of the books aimed at adults follows the argument of the OPOs that donation helps families cope with death. Like the insurance companies, the stress is on the alleviation of the “pangs of the bereaved.” Though it is clear that not every donor family can follow it successfully, the books lay out a sequence, a set of stages of feeling centered around the benefits of organ donation in the face of an otherwise meaningless event.

This template for the secular ritual of organ donation is quite well-established. The stock of cultural resources available to assist its broad acceptance is large (books, television documentaries, newspaper articles and so on). As an indication of how entrenched this view now is, it is significant that books aimed at children have begun to appear. *Precious Gifts: Barklay and Eve Explain Organ and tissue Donation* (Carney 1999) and *Lizzy Gets*

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<sup>3</sup>From the Transweb memorial for Carl Zimmerman.

a *New Liver* (Ribal 1997) both lay out the process of organ and tissue donation for young children. *Precious Gifts* is aimed at 4 to 8 year olds. The publisher’s description notes that the book will help “children and adults understand the process of organ and tissue donation. The determination of brain death and its meaning is clearly portrayed. The process of family decision-making is poignantly illustrated. A list of words and definitions is provided to enhance understanding.”

The place of children in this cultural account is interesting in another way, too. As organ donation became more common, media attention focused disproportionately on transplant cases involving infants or children. As can be seen from Figure 2, *New York Times* coverage of child transplants rose and fell during the 1980s. Coverage peaks in 1984 (at more than 38% of total coverage) with the story of Baby Fae, the “baby with the baboon heart”. It remains high throughout the 1980s. Most of these stories are about children getting transplanted and (often) dying shortly afterwards. By 1995, coverage of children falls to about 7% of total coverage and stays there. The era of transplant “poster children” in the 1980s may have done much to acquaint people with organ donation.

[FIGURE 2 ABOUT HERE]

We might be inclined to think it quite natural that organ donation should become a part of the mourning process for a family member lost in an accident. This would be a mistake. Indeed, in the early 1980s it was not clear to those involved whether a request for organs would make things better or worse for the grieving family. Writing in 1985, Arthur Caplan noted that “Often the [nursing] staff may be concerned about the impact of the donation request on the acutely grieving family and may preclude the family’s opportunity to donate [by not asking]” (Caplan 1987, 264). Integrating organ donation into grieving required a good deal of cultural work. A combination of survey research conducted by the OPOs, widely-circulated first-hand testimony from donor families, and required request laws that deprive nurses of any discretion in the matter have essentially eliminated the idea (at least amongst transplant professionals) that a sympathetic request

for organs could cause harm.<sup>4</sup>

*A moral act for family or community*

Religious leaders play an important role in making practices like organ donation acceptable. Church authorities in many religious traditions support organ donation. Their main concern has been to assure that the donation is altruistic, and that the donor is dead before the organs are removed. The accurate determination of death is important for theological reasons. In Catholic teaching, the soul must have left the body before organ harvesting can occur. Any tendency to redefine the moment of death is suspicious, as this might make it easier for doctors to give up on patients in order to harvest their organs.<sup>5</sup> I cannot discuss the issue of defining brain death here (see Zaner 1988, for a detailed discussion). But insofar as there is no money involved, and the donor has died, most Christian church authorities are not against organ donation.

Compared to this, Orthodox Judaism has had more trouble assimilating organ donation to existing law and practice. There is more opposition to organ donation, and religious authority is more divided on the issue. Rabbis who favor it have had to make strong efforts to integrate organ donation into existing theology and ritual. Those in favor say “the preservation of human life supersedes all *halachic*<sup>6</sup> prohibitions, except for the three cardinal sins: idolatry, adultery and murder. Thus, procurement of cadaver organs for life-saving purposes need not pose a major problem, since the various prohibitions cited would be overridden by the supreme requirement to save a life” (Twersky et al. 1991, 190). A difficulty is that influential *halachic* opinion

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<sup>4</sup>But see Norris (1990) for an argument about why required request laws have not succeeded as expected. For survey evidence that donor families are more likely to say that donation helped them deal with their loss, see Batten and Prottas (1987). In addition to these efforts, the position of the Organ Recovery Coordinator became increasingly professionalized, as OPOs accumulated specialist knowledge about how to intervene. See Sammons (1988), Strange and Taylor (1991), Williams et al. (1991), and United Network for Organ Sharing (1995, nd).

<sup>5</sup>To guard against this, there is a long-standing professional separation between the doctors who declare a patient dead on the one hand, and the transplant teams that harvest the organs.

<sup>6</sup>The *halacha* is the accumulated body of law and ethics in Orthodox Judaism.

identifies the absence of a pulse as a necessary condition for determining death. This is almost never the case with organ donation, where the potential donor is brain dead but otherwise functioning. In their educational and promotional material, UNOS and the OPOs circulate material from Jewish authorities favoring donation.<sup>7</sup>

Even though most religions accept or encourage voluntary donation, these endorsements go against the grain of many other religious views on questions about human goods and human life (in cases such as genetic engineering, fetal research, and so on).<sup>8</sup> Support for organ donation in the Catholic church is weakened by concerns over the definition of brain death, which leads some conservative church members to oppose organ donation. When added to the difficulties within Judaism, is not surprising that many people believe that religious officials oppose donation. A 1990 survey found that 61.5% of respondents believed that some major Western religions do not support it (Horton and Horton 1990). In response, UNOS and various individual OPOs collect and publicize official religious policies on organ donation and offer guidebooks to ministers on their role in the process (United Network for Organ Sharing 1998).

For most churches, the problem of organ transplants solved itself once they solved the problem of brain death. The churches focused on overcoming the problem of organ organ donation's proximity to death. The other boundary problem — where human goods change hands for money — remained in the background, as there seemed to be little prospect of the legal sale of organs in any form. This may change, as I discuss below.

### *A way to ensure one's memory*

The third feature of the cultural account of organ donation is the idea that donation is a way to live on (and do good) after death. Donor families, OPOs, and the media all express this sentiment. The “Donor Memorial

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<sup>7</sup>See “Organ Transplant: soon it may be a routine part of the Jewish Death Ritual.” *The Jewish Voice* December 1996.

<sup>8</sup>There is an overlap here. Although fetal tissue and organs may be harvested for medical use, most churches are against this, as the fetus involved will normally have been aborted or grown in a test tube.

Quilts” project (like the AIDS quilt) remembers the sacrifice of organ donors. A more direct expression of this idea is that the donor spiritually as well as physically lives on in the recipient. Batten and Prottas’s (1987) follow-up study of organ donor families found that 68% of them agreed that the deceased relative could live on in someone else through donation. This sentiment is very common in the journalistic literature.<sup>9</sup> OPOs also draw on it in their efforts to recruit people to sign organ donor cards.

For example, The Sharing Network (a New Jersey OPO) organizes public information sessions where donor families and transplant recipients talk about their experiences. One, Jack Locicero, lost his daughter Amy in the 1993 Long Island Railroad shooting, when Colin Ferguson killed six people on a crowded commuter train. Locicero and his wife decided to donate Amy’s organs. In his talk, he describes how they came to meet some of the recipients, and how they have become “like family” to them since then.<sup>10</sup> The families feel that Amy lives on through her transplant. Kin-like ties have developed between them, especially between the Lociceros and the recipient of Amy’s heart, a woman named Arlene. They visit one another. She sends flowers to Amy’s mother on Mother’s Day. When they first met, Arlene embraced Amy’s mother and said, “The heart that beats in me once beat in your womb.”

I highlight this case because, although such stories are common in the media, they are rare in practice. In the Locicero’s case, they ended up meeting the recipients of their daughter’s organs because of the publicity that the shooting received. *People* magazine picked up the story and traced the patients who had received the organs. Donor families are normally given the age, gender, and general location of each recipient. But much of the donor literature (though not the written OPO material) focuses on

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<sup>9</sup>This idea can never be entirely symbolic, since the recipient does carry a physical piece of the donor alive inside them. There are also much stronger versions of it: In her memoir *A Change of Heart*, Claire Sylvia claims that after her heart-lung transplant she developed personality traits — including new tastes for food and clothes — that she later discovered were characteristic of the 18-year-old man her new organs came from (Sylvia 1997).

<sup>10</sup>Quotes are from notes of a talk given by Jack Locicero, delivered at Princeton University on April 20th 1999.



these unusual cases where families meet. The idea of the continuing life of the donor in the body of the transplant recipient is especially forceful in these cases. Pekkanen (1986, 213) describes one such meeting. One family member says “I don’t really see why we should have rules against these meetings . . . I sure think it would help heal a lot of anger and hurt.”

The available evidence suggests that donor families are unhappy with the information they receive about the recipients of their gift. In a valuable but unpublished pilot study, Banevicius (1992) interviewed donor families about their experiences with donation. She found that all the families would have liked to receive some follow-up information about the recipient. One suggested a letter “maybe once a year . . . I don’t need to know every breath they take but you would like to know that they’re okay or they’re not okay” (Banevicius 1992, 35). Another respondent asked

Wouldn’t it be nice to be able to drop somebody a note, saying congratulations I’m glad everything went well for you. It was my relative who’s [*sic*] part you received and I’m so glad to know you’re no longer on dialysis, or that you can get up and go to work or go play tennis again. But there isn’t that kind of an exchange, and why? (Banevicius 1992, 36)

Most donor families will not meet “their” organ recipients. The feeling that their loved one lives on must be more abstract. Again, narrative accounts act as a road map for the emotions. They show how donors and donor families can have a meaningful sense of the continuing survival of the donor, and a resulting emotional tie between the families. This ideal must be promoted: it is not the only possible response. Evidence for the alternatives is available from both donors and recipients. Victoria Poole’s *Thursday’s Child* (1980) describes her son Sam’s illness and eventual heart transplant. After his transplant, Sam reacts to his new heart like this: “My new heart likes me; I can feel it. Boy, am I glad I don’t ever have to know where it came from or whose it was. I don’t ever want to know. It’s my heart now, and nobody is going to take it away from me” (Poole 1980, 257). This attitude is not found in the more recent literature.

On the donor family side, Banevicius found that although the families wanted more information, they were not always happy when they got it. In particular, four of her ten respondents were surprised and somewhat upset to find that “their” transplant recipient was not who they imagined. One said

There was a 42 year-old man that had gotten the heart and in a way it was, which I now realize is silly, but it was almost a disappointment that it wasn't a 19 year-old girl. It could be because it would have been like my daughter was living again because, it would have been someone the same age she was (Banevicius 1992, 38).

And another:

I found it a little bit disconcerting that an 18 year-old heart went into such an — I don't want to say such an old person but it would be my hope that it would be someone younger, that would have 40 or 50 years left of their life. I don't want to say it was a waste, but I think that it would be more valuable maybe in somebody in their 20s (Banevicius 1992, 38).

These reactions, on both sides, again point towards the active construction of a particular way of understanding the transplant process, and how the official version may diverge from the complex feelings of donor families and recipients. The dominant interpretation, as found in the Locicero's experience and most of the book-length accounts, is perhaps the better, more satisfying one; but it is not inherent to the experience of donation.

## THE EXPRESSIVE ROLE OF MONEY

The National Organ Transplantation Act of 1984 prohibits organ sales. It was instituted partly in response to several reports about people trying to sell kidneys or corneas through the newspapers. The efforts of Dr. H. Barry Jacobs provided a further spur. He planned to buy organs from around the

world and sell them at a profit to those who needed them (Kimbrell 1998, 30). Public opposition to such schemes has remained high, despite the organ shortage, and politically the idea has long been thought untouchable.

Organ procurement is a delicate affair that must be handled with great sensitivity if it is to work at all. Those in favor of a purely altruistic system would say that this need for sensitivity and respect is one of the strongest arguments for keeping money and the market as far away from potential donors and their families as possible. They argue a gift is the only form of exchange appropriate to such a situation. To offer cash for organs would be obscene. Their opponents retort that the real obscenity is a chronic shortage that could be solved by the market. Proposals for market solutions to the organ shortage have been gaining ground recently in the bioethics literature. In the Introduction to their recent anthology on the subject, Caplan and Coelho (1998, 11) note a shift towards arguments in favor of commodification: “Proposals for outright organ sales are suggested by authors who only years earlier had summarily dismissed any commodification of organs.”

This change in attitude seems to be driven in part by the increasing gap between the number of available transplant organs and the number of people who need one. Both in theory and in practice, bioethicists and the transplant community have begun to look for a way to increase the organ supply using some financial incentive. Perhaps because the feeling rules for altruistic organ donation are now well in place — people know what it is, what everyone’s motives are, and how they ought to react — using money to reduce the shortage now seems more plausible. The key to understanding the role of money in this area, I argue, lies in its expressive rather than its instrumental qualities. Rewards are set up so they are commensurable to the organ being exchanged (Espeland and Stevens 1998); the payment reimburses the donor in an appropriate way.

### *Payment schemes in theory*

As noted above, the normative question — should organs be bought and sold? — tends to overwhelm the empirical one. From a sociological per-

spective, we should be interested in the practical solutions that emerge. Following recent work in economic sociology, I argue that we should expect money to play an expressive role in the exchange of organs. Zelizer's (1994) work on money is about the myriad efforts people make to arrange and earmark different transfers with tokens of payment so that they express the social relationship between the parties. These efforts become especially creative in cases where a transaction involves something thought to be beyond the reach of utilitarian calculation.

If we look at proposals for organ sales, we find this expressive aspect becomes more prominent the more practical the proposal is thought to be. Early versions called for a cash bounty to be paid to the donor family on receipt of the organs. This idea is no longer discussed. Instead, those in favor of commodifying organs are careful to qualify what they mean. For instance, Blair and Kaserman, strong advocates of a market for organs, say that

... [b]ecause the issue of organ markets is so emotionally charged and often misunderstood, let us be clear about what is not being proposed. We do not propose barkers hawking human organs on street corners. We do not envision transplant patients, or their agents, dickering for a heart or liver with families of the recently deceased. We do not advocate an auction in which desperate recipients bid against each other for life-sustaining organs (Blair and Kaserman 1991, 421).

Instead, their solution is to offer potential suppliers "some fixed payment (either in cash or in the form of a tax credit) in exchange for entering into a binding contract that authorizes the removal of one or more of their organs at death" (Blair and Kaserman 1991, 421).

Why should they bother with this qualification? Such efforts to distinguish appropriate from inappropriate sales suggest that even market advocates are aware of the need to mark or transform the place of money in this context. The focus on appropriate *tokens* of payment is important. Certain exchanges are ruled out, especially cash payment at the point of sale. In-

stead, less visible payments are proposed, usually involving money given at a different time, well in advance of any organ procurement. Even these payments may be further restricted to, for instance, a health insurance premium reduction (Hansmann 1989). The futures market created is for an *option* on the organ, should it ever become available. Under such a system, most people's organs would not come up for donation, as they would not die in the appropriate circumstances. In contrast to early schemes that proposed paying the family several thousand dollars (estimated prices varied widely), the amount of money on offer is small. In addition, the form of the payment is commensurated to the item being purchased. The seller receives a small annual reduction in health insurance costs, not a check, a holiday in the Bahamas or a gift voucher to spend at Wal-Mart. The uncomfortable image of paying cold cash for a warm kidney is kept well away.

#### *Payment schemes in practice*

These carefully marked and delimited exchanges are just beginning to appear in practice. In March 1999, state health officials in Pennsylvania announced that they would soon begin offering a \$300 stipend to help donor families cover funeral expenses. This is the first time that a definite cash amount has been introduced by an OPO in connection with donor families. Families will not receive this money in cash. In fact, it will not be paid to them at all, but to funeral homes. A spokesperson for The Gift of Life Program (the Delaware Valley's OPO) said at the time that "This is absolutely not buying and selling organs . . . This is about having a voluntary death benefit for a family who gave a gift."<sup>11</sup> But of course, the OPO introduced the scheme in order to boost donation rates. ("The intent is to test it and see if it makes a difference to families" said the same spokesperson.) This is exactly how we would expect money to be introduced in such a case: it might be expected to act as an incentive, but it cannot be presented as one.

Programs such as these could make those who have already struggled to accept organ donation uncomfortable about it again. If the Pennsylva-

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<sup>11</sup>"Pennsylvania Set to Break Taboo on Money for Organs." *The New York Times* May 6th 1999.

nia scheme is widely implemented, we can expect the arguments as Zelizer documents for life insurance. It is an open question whether the Churches will reconcile themselves to compensation for organs. From the life insurance case, we can expect there to be two sticking points. First, as I have been arguing, the form of the payment will be crucial. Indirect, non-cash transfers (as in the Pennsylvania scheme) will probably be acceptable.

Second, the beneficiary of the transfer also poses a difficulty. Most proposals for futures markets in organs try to eliminate the role of the donor family by making a contract with the donor. But in practice, it is donor families that make the decision to donate, They are the real donors, in fact. Even if the doctors know their patient had a preference for organ donation (perhaps they carry an organ donor card, for example), in practice hospital staff will always defer to the family's wishes. If they refuse consent, the organs will not be harvested. This is so even where organ donor cards are witnessed legal documents. The central role of donor families is a big stumbling block to the implementation of schemes of the kind proposed by Hansmann (1989) or Blair and Kaserman (1991).

How commodified will exchange in organs become? At present, organs are given as gifts, and for-profit exchange in them is illegal. However, the media evidence shows that discussion of cash incentives for organs has consistently increased since the late 1980s. Figure 3 shows a smoothed plot of the number of *New York Times* news items mentioning financial incentives for organ donation over a twenty-year period, as a percentage of all stories about organ donation. The jump in coverage around 1983-84 is caused by early reports about people trying to sell their kidneys, and the subsequent passage of the National Organ Transplantation Act of 1984 (which banned the sale of organs). After the act passed, news items about organ sales or financial incentives remained at about 5% of all organ donation stories for several years. Beginning in 1990, coverage begins to climb again. Later items tend to be policy-oriented discussions of financial incentives as a potential solution to the organ shortage, rather than news stories about organ sales.<sup>12</sup>

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<sup>12</sup>Over the period of the sample, horror stories about organs-for-cash do persist, but

[FIGURE 3 ABOUT HERE]

It is interesting to ask whether the rise in “market talk” about donation is related to the fall in the relative number of stories about infants or children and transplantation. One interpretation is that children are an index of the sacred. Since the late 1980s, transplants have become more and more routine (from a medical point of view). At the same time, demand pressure on the system has increased severely. Associating organ transplants with children might have made it more palatable initially, but such associations might be a liability in the context of a severe shortage and the possibility of a market for organs.

## COMMODIFICATION AND ACCOUNT-GIVING

Nevertheless, donor families are not paid cash for their decision to donate. But both the trend of public discussion documented in Figure 3 and policy experiments like the Pennsylvania program suggest that money is being introduced to the act of donation in subtle ways. Does this mean organ procurement will ultimately be market driven?

Some economists take this view. Their argument is that the reasons and excuses offered are just window dressing for the simple expansion of the market into a new arena. The life insurance case shows that people often resist the market on moral grounds only to later accept it as expedient and sensible. Likewise for organ transplants. What would be the problem with an organ market? If it makes you feel better to call the sellers “donors” (as with human eggs), then go ahead. But the suppliers will still get the market rate, whether you call them donors or not.

In contrast, work in economic sociology, along with the efforts of some legal theorists (Radin 1996, Sunstein 1997), points in a different direction. Charles Tilly comments that, from Zelizer’s perspective, “what appear to be narrowly rational economic transactions actually result from pursuit of

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become almost exclusively concerned with foreign reports of organ sales, particularly from India, South America and Southeast Asia. These stories are excluded from the data in Figure 3.

meaningful social relations. Hence fears that monetization and commodification are dessicating social life have their causality backwards” (Tilly 1999, 341). In this volume, Deborah Davis examines the different “logics of entitlement” which Chinese focus-group members used to resolve hypothetical conflicts over property ownership. Different rationales were available, of which market-logic was only one. “Participants” she says, “weighed competing property claims within a moral framework that entwined the logic of family justice with practices of both the state and the market”. Davis’s respondents resolved their conflicts by establishing “the property rules that applied when the dwelling first became the family home”. Once this was done, the basic relations between the participants were also known and the right logic to apply became clear. In these sorts of cases, the application of a particular logic of action or the choice of a particular tokens of exchange are fundamentally tied to some underlying social relationship.

Is there evidence to help choose between these alternatives? Some cases do seem better suited to one side than the other. Egg “donors” who are paid thousands of dollars for their services support the window-dressing view. On the other hand, the organ case raises the question of why there should be so much window dressing in the first place. Why should people go to such enormous efforts to distinguish forms of payment and ritualize exchanges as they do if it didn’t express something besides a simple preference?

Even in the restricted area of human goods, there is a good deal of variation that does not conform to any simple pattern. Cash for organs is out of the question at present, but direct payment to women for their eggs is routine. Is the distinction therefore between renewable and non-renewable body parts? This is a common explanation, but it is wrong. Except in special circumstances, whole blood cannot be bought from blood donors. In fact, a large U.S. cash-for-blood market was dismantled in the 1970s — a clear counterexample to the idea that market exchange must spread to everything in this area sooner or later.<sup>13</sup> This example should

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<sup>13</sup>The mistaken idea that market vs nonmarket exchange neatly lines up with renewable vs non-renewable body parts probably persists because many people wrongly believe that there is for-profit blood collection in the United States. In fact, almost all of the whole



give pause to both sides. On the one hand, markets do not inevitably win out. There is no slippery slope towards commodification. But on the other, there is no insuperable obstacle that prevents for-profit markets in human goods from being set up. Just such a market existed for blood until 1974, and still exists for plasma. The correspondence of types of goods to kinds of exchange systems is variable, and not an immutable fact about human nature. A sociology of commodification ought to be able to account for this variability.

Further, the legitimate *expression* of a market interpretation might vary by social position, or by the frequency of the transaction. Most donor families are only in that position once. Medical professionals who are repeatedly involved in organ exchange may have a “backstage” view that sounds more cynical. Backstage cynicism is not uncommon in medicine. For instance, in the U.K., when a person dies a doctor must fill in a form registering the cause of death. There is no charge to the next of kin for this. However, if the body is to be cremated, the doctor charges for the relevant form, and also gets another doctor to fill in a similar form, for a total charge of about sixty pounds. This is known in the trade as “Ash Cash.” Even here, though, the market-talk may represent rhetorical gallows humor more than a real financial incentive (see Radin 1996, 79–101, for a discussion of the relationship between market rhetoric and commodification proper).

Within genuinely cash-oriented markets, some interesting conventions still exist. Egg-suppliers will normally receive an unspecified gift in addition to the money. The following newspaper advertisement (from the *Columbia Daily Spectator*) is typical: “Although our gratitude cannot be measured in dollars, if we were in your shoes, the least we would expect is: \$6,500 plus expenses (and a gift).”<sup>14</sup> Even sperm donors, who are at the very bottom

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blood collected is freely donated. There is a market for plasma, which complicates the issue. But this only reinforces the point: there is no convenient biological divide that maps on to the social organization of exchange. See Healy (1999) for further discussion.

<sup>14</sup>“We have had some fabulous gifts . . . We have had donors sent on cruises, we have had a year of tuition paid. The donor doesn’t know what the gift is going to be. She just knows that there will be a gift, so that way she’s still giving her eggs without undue compensation or any form of bribery.” So says Teri Royal of the *Options* Egg Donor Agency. Quoted in Mead (1999, 62).

of the status and income hierarchies in the world of human goods, are still donors rather than vendors. It seems that, even if money is involved in these exchanges, people do not want to account for them in market terms. They repeatedly insist that they are not being motivated by the money. If experiments like the Pennsylvania scheme have the effect of increasing the donation rate, then the trend of in-kind reimbursement is likely to accelerate. But the official account of donation will probably not speak in market language.

Disguised payments, benefits and gifts to donor families are likely to play an increasingly important role in the organ supply. Is this commodification? It does not conform to the altruistic vision of organ exchange. But it is not the nightmare world of cash for kidneys that many opponents of commodification have in mind. Nor does it much resemble the system of binding contracts with future donors proposed by the more thoughtful advocates of the market. From what we know about the motives of donor families, the organizational effort required to procure organs, and the fragility of consent, there is every reason to believe that these complicated arrangements are a necessary part of motivating the consent to donate, and not just window-dressing that could be dispensed with if only we were honest with ourselves.

## CONCLUSION

Contemporary debate about medical technology and the market is attracted by novelty, by the brave new worlds opened up by genetic engineering or cloning or xenotransplantation (Cooper and Lanza 2000). It is often normative, asking what ought to be done (to commodify or not to commodify) with particular goods. These are important problems, but I have taken a different tack here. I argued that economic and cultural sociology contribute important insights about how people manage these problems. This approach, developed from historical cases of commodification, makes good empirical predictions about the organ industry. I argued that the chief lesson of these studies is that the empirical reality of organ exchange is likely to be more differentiated and carefully managed than standard debates about

commodification might lead us to believe.

Though outside the range of the usual comparison cases, the analogy I began with between the life insurance and organ transplant industries is rich. Life insurance and organ transplants threaten sacred beliefs about death and the body. They bring the threat of utilitarian calculation and the negative influence of money. One possible reaction is to ban the corrupting practice for good. But more often, the practical benefits are large, or the promoting organizations are powerful. The new practice can be reinterpreted so that it can be incorporated into existing ritual, and reconciled to existing understandings. The cultural account of organ donation can be seen in these terms. Transplant advocates did not force their ideas on an unwilling public. Neither did the account of donation appear by magic to solve the problem of procurement. Rather, there are many ways that donation might be understood. The cultural work of transplant advocates produced the public version we ended up with. They found ways to incorporate donation into death rituals; they made signing a donor card a morally worthwhile action; they associated the donation with a kind of social immortality. The result is that public opposition to organ procurement is now almost unknown in the United States, even though people do not like to sign donor cards, families often refuse consent to donate, and the available evidence suggests a much wider range of responses to procurement than the official account suggests.

As the organ shortage has worsened, OPOs have begun to explore new ways to give people the incentive to donate. Proposals for commercializing the system by contracting with potential donors misunderstand both how the procurement process works and how people understand it. Paradoxically, opposition to commercialization is buttressed by the same arguments for the “gift of life” that helped legitimate donation and transplantation from the 1970s onwards. In response, transplant advocates in favor of some kind of incentive system are beginning to develop payment systems that reimburse without corrupting. A new phase of account-making seems to be underway.

The standard commodification literature tends to miss this organizational and cultural work. Instead, it focuses on abstract questions of commodification or on difficult (and often quite unusual) cases (Zaner 1988,

Childress 1989, Churchill and Pinkus 1990, Lamb 1990). Some bioethicists are concerned with the practical application of moral theory (Caplan 1994). But the field as a whole has little to say about the how individuals and organizations have found ways to give meaning to transplantation. Similarly, although some scholars have developed sophisticated conceptual accounts of commodification (Anderson 1993, Radin 1996, Sunstein 1997) they have less to say about the organizational effort and cultural work that go into making these exchanges socially acceptable.

I have argued that, as with similar areas that deal with death or the exchange of human goods, the transplant community has tried to account for itself as a moral actor in a comprehensible and convincing way. In the process it has developed a body of secular ritual to help manage a fragile transaction. This account is under increasing pressure as the gap between supply and demand for organs continues to widen. The key to understanding what exchange in human goods will look like in the future does not lie in novel technologies or moral recipes. Rather, what is important is its resemblance to other markets — for insurance, blood, children, or sex — that are subject to similar cultural work and face comparable organizational problems. Strategies used to make exchanges socially acceptable in these cases will also shape the institutionalization of organ donation.

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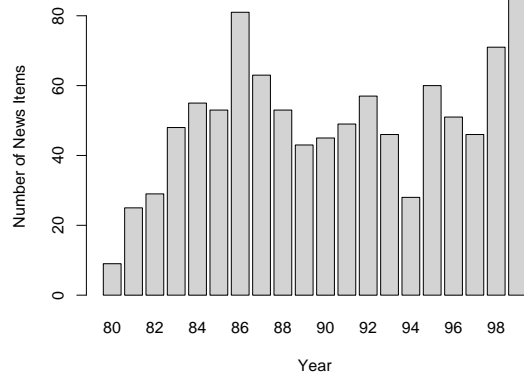


Figure 1: *Number of New York Times news items on organ transplantation or donation, 1980-1999.*



Figure 2: *Smoothed (running median) plot of number of New York Times stories about infants or children, as a percentage of all stories about organ donation or transplattation, 1980-1999.*

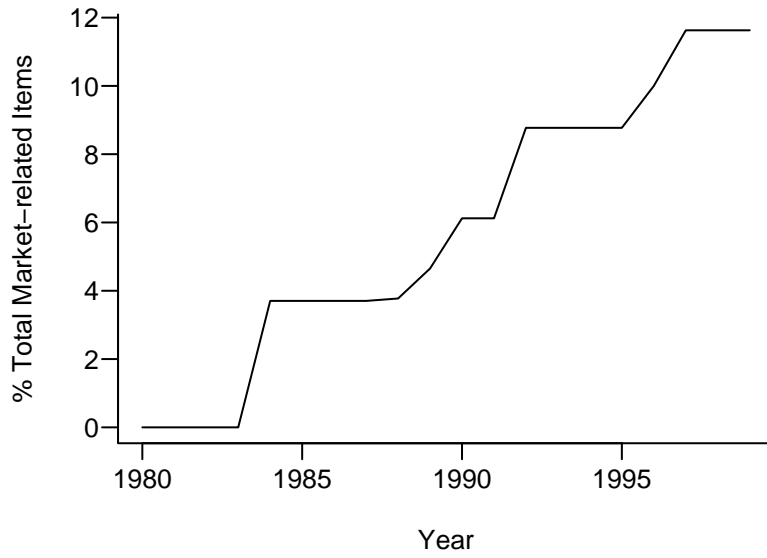


Figure 3: *Smoothed (running median) plot of number of New York Times stories mentioning financial incentives for organ donation in their headline or lead paragraphs, as a percentage of all stories about organ donation, 1980-1999.*