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**The Gift of Life:**

**Understanding Organ Donation and Gift Exchange through Literature**

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## ABSTRACT

My training as a transplant surgeon included intensive education about the anatomy and physiology that makes transplantation feasible, but we rarely examined the act that makes transplantation possible: organ donation. Here I use literature to explore the idea of gift giving as it relates to transplantation. Although organ donation is commonly referred to as giving the “gift of life,” the metaphor of giving a gift may not completely encompass the complicated emotions, motives, and expectations involved. In Chapter 1, I present a brief history of organ transplantation and discuss how the concept of organ donation has been defined legally and administratively in the United States. Chapter 2 explores the idea of gift giving, focusing on the work of Marcel Mauss and comparing his construct with the idea of charitable gift giving. Chapter 3 is a close reading of Richard Selzer’s short story “Whither Thou Goest,” in which a widow deals with the aftermath of donating her husband’s organs. In the final chapter, I examine John Irving’s novel The Fourth Hand as it explores the relationship between the recipient of a hand transplant and the widow of the donor. Selzer’s story better reflects the current process of organ donation consistent with charitable gift giving, whereas Irving’s novel provides a potentially helpful alternative view of the relationship between donor and recipient. Both stories highlight the emotional complexities involved in the relationships between donor and recipient, but neither work completely conforms to Mauss’s construct of gift exchange. These stories provide a way to explore organ donation and its effects on both donor and recipient.

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## INTRODUCTION

Despite the years and years of training I went through to become a Pediatric Transplant Surgeon, I remain routinely flummoxed by ethical questions that arise in my practice. One such episode occurred a few years ago. My patient was a boy who received a liver transplant from a deceased donor. Normally, when a patient receives an organ from a recently deceased donor, any identifying information is withheld from the recipient and his or her family, a practice I had internalized without question. The justification for this protocol is that the donor family is experiencing the deep grief of losing a beloved family member, and, in return for the priceless gift of donating the organs, an elaborate system is upheld to protect that family from unwelcome intrusions. However, in this case, that elaborate system was not enough. It is impossible to say how the leak of information started, but it is easy to imagine how it was passed along from person to person until the mother of my patient heard the information she was not supposed to hear. Hospitals are often akin to high schools with a propensity for dramatic rumors to spread quickly. My patient's mother had ascertained that the donor was a boy who died in a traumatic accident, his approximate age, and the city where he died. Two days after the successful transplant, she searched the obituaries in that city on Google, and found not only the donor's actual name but also his correct home address. She told our transplant coordinator that she was planning to send flowers, so we were able to intervene before she had contacted the donor's family.

Ever since, I have questioned the process that I had for so long accepted as proper procedure. I could relate to the donor families who had lost a loved one, as I had experienced the death of a parent while in medical school. At that time, my family and I would not necessarily have welcomed the presence of strangers during our grieving process. Even a small token such as flowers would have been viewed as an intrusion. But my patient's mother's determination to express thanks, her persistence to find the information even as my team had withheld it, has remained with me. Even though I had been

performing transplant surgery for years, the relationship between the deceased donor family and recipient was not something I had examined closely up to that point, and was not something I even remotely understood.

I do not routinely have contact with the donor families who have generously donated organs of their loved ones. The transplant teams rarely have the opportunity fully to consider the psychological implications that organ donation has on these families. Even those medical professionals who do have personal relationships with the donor families, the intensive care physicians and trauma surgeons and many others involved at the time of death, likely do not interact with the families after the patient has died and the family leaves the hospital. Transplant professionals do continue to see the recipients for many years, but in clinical situations the psychological aspect of accepting a valuable gift from a stranger is rarely addressed. As a medical team we are focused on recovery from the surgery, making sure the patient is taking their medications, and a million other worries that center on the physical body rather than the psyche. In addition, even if an organ recipient did have misgivings, I am not sure that he or she would feel comfortable confiding in their team, since, in my experience, patients tend to be very respectful of not wanting to “waste” our time and want to avoid appearing ungrateful.

In contemplating the relationship between donor and recipient, I kept returning to the idea of the “gift of life” – a phrase used to encourage members of the public to be organ donors. This idea is ubiquitous throughout advertisements and informational material presented to the public. It has also been embraced in popular media, such that it is widely encountered in print and television human interest stories that portray the triumphs of organ transplantation. The idea of a gift would appear to be a suitable metaphor for the idea of organ donation. But it strikes me as a simplistic way to describe the complicated emotions and motives that donors and recipients may experience. Although transplantation often represents a time of joy for the recipient, it is a time of grief for the donor family who has bestowed this “gift.” The matter of describing organ donation has similarly challenged



sociologists, ethicists, and anthropologists, and there exists a rich body of research in those fields concerning the question of how to view organ donation.

Without the opportunity personally to speak to numerous donor families, an alternate method to consider these interpersonal relationships is to use literature. The idea that organs from one human can be used to create or sustain life in another human has fascinated artists for centuries. There are almost too numerous stories, novels, and films to count that address the ethical, psychological and interpersonal aspects of transplantation. Literature offers a window into the lives of others that can lead readers to understand a lived experience different from their own. Thus, I believe fiction can be a useful adjunct when considering the aspects of medicine that involve ethics, relationships, and emotions.

For this project, I begin by presenting a brief history of organ transplantation, followed by a discussion of how the concept of organ donation has been defined legally and administratively in the United States. Although practices have changed since the inception of the field, current standards characterize deceased organ donation as voluntary, altruistic, and anonymous. Living organ donation is likewise considered to be a voluntary act, although usually not anonymous. For context, I describe the process that either the family of a deceased organ donor or a living donor undergoes in our current system. The second chapter explores the idea of gift giving, focusing on the anthropologic work of Marcel Mauss and comparing his construct with the idea of charitable gift giving. Mauss's work represents gift giving as a means to reinforce interpersonal and societal relationships through this exchange. He delineates three requirements for gift giving, including the obligation to give, the obligation to receive, and the obligation to reciprocate. Without these three conditions, gift exchange would weaken rather than strengthen relationships. This is in contrast to the idea of charitable gift giving, which is often anonymous, with no expectation of any reciprocal action. I then consider how

organ donors and recipients experience the process of organ donation, and whether that experience conforms with either of these paradigms.

The third chapter is a close reading of Richard Selzer's short story "Whither Thou Goest," in which a widow deals with the aftermath of donating her husband's organs. Although her initial experience reflects the current process of organ donation consistent with the idea of charitable gift giving, it aggravates rather than alleviates her grief. The story follows her journey to understand what donating her husband's organs means in terms of her own ability to accept his death. In the process, she reaches out to one of the recipients, only to find that he does not want any contact, giving readers an example of conflicts that may occur when donor and recipient have different expectations about what the organ donation entailed. Finally, in the fourth chapter I examine John Irving's novel The Fourth Hand as it explores the relationship that develops between the recipient of a hand transplant and the widow of the donor. Although the universe Irving creates seems very close to our current medical environment, there are some differences that allow Irving to explore alternative approaches to organ donation. Irving's depiction of their relationship does not conform strictly to either Mauss's view of gift giving or the current standard of organ donation in the United States, but rather provides an alternative view of the relationship between donor and recipient that may have advantages over our current system.

With so many works of literature and film to choose from, I focused on these works for two reasons. First, both works can be found in popular culture and are widely available to the lay public. Selzer's story was first published in *Redbook* magazine in the September, 1990, issue. Today *Redbook* would be considered a women's lifestyle magazine, but throughout most of its history it was known as an outlet for literary short fiction, publishing works from such well-regarded authors as Edith Wharton and Jack London. At the time "Whither Thou Goest" was published, *Redbook's* circulation was over 3.9 million paid subscriptions per month (Donaton). Irving has won both a National Book Award and an

Academy Award for Screenwriting, and four of his novels have become New York Times Bestsellers. For his part, The Fourth Hand was his fourth book to do so, reaching the top of the list on July 29, 2001.<sup>1</sup> To a member of the public who has not had personal experience with either the need to undergo a transplant or the misfortune to have donated a loved one's organs, popular works of art may be one of the few opportunities to learn vicariously. As a physician, I have heard many times families and patients express some version of "this isn't like I saw in the movies" when faced with an unexpected health crisis. It is possible that members of the public can develop beliefs about organ donation through popularized fiction, and these attitudes could influence decisions they make in the future, both in terms of deciding to donate and for influencing political and legal precedent. It behooves both the transplant community and academic circles to consider what works of art the public is most likely to have encountered.

Second, both works reflect specifically on the relationship between a donor's widow and the recipient. Both present the opportunity to examine the gift exchange relationship in the setting of deceased organ donation. Selzer's short story is the more realistic of the two, providing a means of assessing critically the practices surrounding deceased organ donation as in the United States. Irving's novel at first appears to uphold contemporary standards of deceased organ donation, but as readers we quickly see that the ethical and administrative norms in Irving's novel are not the same as currently practiced. In this sense, The Fourth Hand is a thought experiment, setting up a "what if" question and then exploring consequences of that alternative reality. Ultimately, it is up to the readers to decide which fictional world is the one the transplant community should aspire towards.

To be involved in transplantation in any way, as donor or recipient, involves aspects of grief, illness, and recovery that are unique to each individual. My hope is that this project allows the reader better to comprehend the process of organ donation through the examples in these works of literature.

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<sup>1</sup> [https://en.wikipedia.org/wiki/Lists\\_of\\_The\\_New\\_York\\_Times\\_Fiction\\_Best\\_Sellers](https://en.wikipedia.org/wiki/Lists_of_The_New_York_Times_Fiction_Best_Sellers), accessed on November 15, 2017.

Whether or not organ donation can be considered comparable to a gift exchange, a better understanding of the experiences of donors and recipients might allow us to provide improved support and care for both parties.

## CHAPTER 1

### A BRIEF OVERVIEW OF ORGAN DONATION IN THE UNITED STATES

#### THE ORIGINS OF ORGAN TRANSPLANTATION

With her famous 1818 novel Frankenstein, Mary Shelley is often given credit for searing the idea into the popular imagination that cadaver organs might be used to create life (Shelley). The image of Dr. Frankenstein pilfering graveyards and taking organs from cadavers in the dead of night has been portrayed through numerous films and reinterpretations of her original story. But precursors to this idea of a living body created from different parts of disparate living creatures existed well before Shelley penned her novel. There are numerous examples of creatures with body parts from multiple species present in ancient mythology. Creatures that combined body parts of different animals were present throughout Greek mythology, such as Pegasus, a horse with wings who could soar through the sky, and the Chimera, an animal described as being composed of various combinations of a lion, goat, and serpent.<sup>2</sup> Humans could also be part of these mythologic hybrids, including the Egyptian Sphinx, with its lion's body and human head, and the Greek Gorgons, women with wings and hair replaced by snakes. Human to human organ exchange was described many centuries before Shelley. According to an ancient Chinese legend, physician Pien Ch'iao was said to have performed a double heart transplant, exchanging the hearts of two soldiers in an attempt to grant each soldier the other's mental attributes (Kahan). The Catholic Saints Cosmos and Damian lived during the third century AD and eventually became the patron saints of surgeons. They were canonized in part due to the miracle of transplanting

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<sup>2</sup> "Chimera" is the etymological basis for "chimerism," a modern scientific term that refers to any organism composed of cells with distinctly different DNA. This term would certainly apply to modern day organ transplant recipients, since transplanted organs would have different DNA than the organ recipient.

a recently deceased Ethiopian man's leg onto a Roman catholic deacon who suffered from a severe ulceration of his leg (Coulehan).

Over time, what had been initially imagined as fantastical began to seem possible, and scientists and physicians proceeded to make organ transplantation a reality. Animal experiments in which a body part from one animal was transplanted onto another of the same species had already been documented in the eighteenth century, before Shelley wrote Frankenstein (Petechuk). By the 1930's, Dr. Yurii Voronoy, a Soviet surgeon, was attempting to transplant kidneys obtained from cadavers into living humans (Matevossian et al.). It was not until 1954 that Dr. Joseph Murray performed the first successful human kidney transplant in Boston between identical twins (Murray and Hills). Unfortunately, not every patient in need of a new organ has the advantage of having an identical twin. As surgical techniques improved and researchers were better able to understand the immune system and how it affected transplanted organs, surgeons were finally able to transplant organs from deceased human donors into living human recipients. During the 1960's, Dr. Thomas Starzl performed the first human liver transplant at the University of Colorado, Dr. James Hardy performed the first human lung transplant at the University of Mississippi, and Dr. Christiaan Barnard performed the first heart transplant in South Africa (Petechuk). Dr. Starzl is considered by many to be the "Father of Transplantation," due to his groundbreaking advances in both the surgical techniques of transplantation and understanding of immunology. He evoked the fantastical concept of transplantation even as he spoke of the scientific advances when he described the scientific discoveries that led to the ability to perform transplants as

. . . like a fairy tale, a fantasy that became reality because of the courage of our patients. The truth is that none of us in the 1950's remotely envisioned the height to which transplantation would rise and the way it has changed the face of medicine. (Altman)

Over the next several decades, the field of organ transplantation continued to grow. By 1990, there were over 15,000 solid organ transplants performed in the United States, and in 2016 this had increased to 33,610 transplants.<sup>3</sup>

Advances in science were not the only limiting factor in promoting organ transplantation as a therapeutic option for certain diseases. Unlike most fields of medicine, organ transplantation relies on a resource that cannot be provided solely by the work of physicians or as the result of medications, surgical procedures, or other technological advancements. Organs can only come from other human beings, whether from a living person or from a deceased donor, and this fact has not changed in over sixty years since the first successful transplant. With the development of organ transplantation as a viable method to treat certain diseases, organ donation became a fundamental part of the process -- without the organs there could be no transplants. But how would the medical field obtain the necessary organs?

#### ORGAN DONATION IN THE UNITED STATES: VOLUNTARY, ALTRUISTIC, AND ANONYMOUS

Acting as a living organ donor can easily be viewed as a selfless act for a loved one, but the act of removing organs from cadavers evokes Shelley's Dr. Frankenstein rummaging through graveyards, an image that would not have been palatable to society early in the history of transplantation in the 1950's and 1960's. In order to avoid associating organ donation with something potentially distasteful, policy makers in the 1960's invoked the idea of giving a gift to introduce the concepts of both living and cadaveric organ donation to the general population (Gerrand). Likening organ donation to the concept of giving a gift was useful because gift giving is a ritual that is recognized as a common practice across most cultures. Thus, the general public would be able to associate a process that seemed foreign to them, organ donation and transplantation, to an act that was not only commonplace but also had

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<sup>3</sup> Based on OPTN data as of October 13, 2017; <https://optn.transplant.hrsa.gov>.

positive connotations. Organ donation from a living donor fits very easily into the construct of giving a gift: a living person who donates an organ donor usually does so out of a spirit of generosity in order that the recipient will benefit from improved health. From a legal and ethical standpoint, it requires that a living donor give informed consent free from any coercion (Sadler, Sadler and Stason).<sup>4</sup> In the case of cadaveric organ donation, however, neither the metaphor of gift giving nor the legal questions are quite as straightforward.

Prior to the era of organ transplantation, the American legal framework for what happened to a dead body was based on English common law. A dead body was not considered property per se, but next-of-kin had the responsibility to dispose of the body and the right to do so as they saw fit. This idea was challenged through an American 1950's court case that ruled a person could have input on the disposition of their body by communicating such wishes prior to death, such as in a will (Sadler and Sadler). During the 1950's and 1960's individual states within the United States created separate statutes to address how a person might designate whether their body could be used for medical or scientific purposes after death. The various state laws differed significantly, but for the most part shared the idea that the process be voluntary, either by a person giving permission prior to dying or through next-of-kin after the death of a potential donor (Sadler, Sadler and Stason; Sadler and Sadler). The Uniform Anatomical Gift Act of 1968 (UAGA) was legislation conceived of and written by the Conference of Commissioners on Uniform State Laws, and later presented to every state legislature in the United States for adoption (Curran). This law aimed to standardize the donation process throughout the United States, providing a legal and ethical framework specific to the act of organ donation after

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<sup>4</sup> The idea of informed consent is itself a complicated topic that touches on all fields of medicine. My goal is not to minimize the difficulties surrounding the issue of informed consent for patients who want to act as living donors, but only to underscore that the relationship between a living organ donor and the intended recipient is by its nature more easily apparent, and thus more readily lends itself to the idea of giving a gift to a loved one. For more information on informed consent, please see <https://www.hhs.gov/ohrp/regulations-and-policy/guidance/fag/informed-consent/index.html>.



death (Sadler, Sadler and Stason). The most significant aspect was the establishment of a process through which an individual could designate his or her wishes concerning organ donation after his or her death, either to consent to donation or to forbid it. The law also established a framework for next-of-kin to make the decision if a decedent's preferences are unknown, but specifically prohibited next-of-kin from overriding any known wishes of a deceased person (Petechuk). Despite this provision, next-of-kin is almost always asked for consent because hospitals fear litigation by surviving relatives (Overcast et al.). By 1971, this law had been adopted in all 50 states and the District of Columbia, thus enshrining the idea that organ donation in the United States be a voluntary process (Sadler and Sadler).<sup>5</sup>

In addition to being a voluntary act exempt from coercion, experts have argued that organ donation should be altruistic without any secondary gain for the donor. Advocates of compensating donors and their families have argued that the supply of potential organs for transplantation would increase with compensation. However, there are many ethical reasons why the sale of organs may not be practical. If subject to the free market, the cost of organs could become so exorbitant that not every patient could afford one. Alternatively, when family members are making decisions on behalf of an ill relative, any financial incentive could be seen as a potential conflict of interest to hasten that relative's death and donate organs (Dukeminier). Paul Ramsey, an ethicist writing in the early 1970's, further

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<sup>5</sup> The United States system for deceased donor organ donation based on voluntary consent differs from the system of presumed consent that is practiced in several other Western countries. In countries with a system of presumed consent, medical professionals may procure organs from any deceased person in whom the organs are considered suitable for transplantation. If an individual or family have some objection to organ donation, it is their responsibility to raise the objection. In other words, the patient or family must "opt out," as opposed to the voluntary system practiced in the United States in which patients or family must "opt in." Some proponents have argued for adopting a system of presumed consent in the United States. This subject has engendered significant debate, but a full discussion is beyond the scope of the current project. For the purposes of this project, both systems share the fact that some form of voluntary consent be given, whether explicit or implicit. To read more about the differences in these two approaches please refer to the papers by Arthur Caplan 1984 and Jesse Dukeminier 1968.

argued that organ donation without any form of monetary incentive gives individuals or their families an opportunity to act charitably while also building a sense of community (Ramsey). This view has continued to influence policy in the United States, with the 1986 Report of the United States Department of Health and Human Services Task Force on Organ Transplantation reiterating that one goal of organ donation is “promoting a sense of community through acts of generosity” (Blumstein). Although not codified in federal statutes, it was standard practice to disavow any type of monetary payment for organ donation. In 1983 Dr. H. Barry Jacobs launched a company that attempted to broker potential living kidney donors with recipients willing to pay. The ensuing public outcry contributed to portions of the National Organ Transplant Act of 1984 (NOTA) which expressly prohibited the sale of human organs (Hazony; Prottas; Petechuk; Joralemon). From that point on, the idea that organ donation was an altruistic gift rather than an exchange of goods, money, or objects was affirmed in United States law.

Public opinion in the United States has supported this interpretation of organ donation as a voluntary, altruistic donation. A survey of family members who had recently agreed to donation of a deceased family member’s organs was compared to responses from members of the general public. When asked whether cash incentives should be given to families who had consented to donation of their loved ones’ organs, only 31% of the general population respondents agreed and only 16% of the donor families agreed. When asked whether those families should receive some form of tax credit, 45% of the general public respondents agreed and 35% of the donor families agreed (Batten and Prottas). Other authors have added that financial reward or reimbursement would not only put a burden on the government to provide such payments, but could also lead to diminished quality of the organs (Hazony). Comparisons have been made to the supply of donated blood after restrictions allowing payment for blood were implemented. Titmuss compared the British system in which blood is donated solely by

volunteers to the US system in which blood donations can be compensated, and concluded that the latter leads to decreases in both quality and quantity of the blood supply (Titmuss).

Organ donation in the United States has also developed to become an anonymous process, at least in the case of donation after death. Living donation almost always involves situations in which there is some preexisting relationship between the potential donor and intended recipient, a fact that will inform our later discussion of gift giving.<sup>6</sup> This current practice differs from the early days of transplantation, in which information about both the donor and recipient was often disclosed to the respective families. Some practitioners felt that the families were entitled to this information because the exchange of organs was such a personal, intimate act. The hope was that the recipient would better appreciate the organ if he or she knew details about the donor, and the donor family would find solace in knowing personal details about the recipient or recipients (Fox and Swazey "Organ Transplantation as Gift Exchange"). Over time this practice has evolved to one of maintaining anonymity. Transplant professionals became uncomfortable with the way relationships developed between donor and recipient families. Transplant teams observed that some donor families came to believe that recipients may in some ways be a "replacement" family member, a belief referred to as "fictive kinship." Professionals felt the need to protect the recipient from feelings of obligation to the donor family that might lead the recipient to participate in a relationship with which he or she is uncomfortable (Fox and Swazey "Gift Exchange and Gatekeeping"; Fox and Swazey "Organ Transplantation as Gift Exchange"). Despite misgivings however, examples of donor and recipient families starting and maintaining long term relationships certainly occur (Joralemon). Problems only occur when the two parties disagree

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<sup>6</sup> There are instances in which a living person donates an organ, typically a kidney, to be transplant into a patient who has been on the organ waiting list rather than someone the donor knows personally. In the field of transplantation, this is sometimes referred to as an "altruistic" donation. However, the more appropriate term, used by the Organ Procurement and Transplantation Network, is a "non-directed" donation (<https://optn.transplant.hrsa.gov/resources/ethics/living-non-directed-organ-donation/>). As discussed in the previous section, many if not all organ donations should be considered altruistic.

about whether a relationship should exist or how intimate the relationship should be, and the transplant community has thus agreed to err on the side of caution to protect those families, either recipient or donor, who prefer not to enter into such a relationship. Currently, anonymity is maintained by all members of the transplant teams initially at the time of donation and transplantation, although this practice is upheld through standard practices and policies rather than via legal statutes.

## THE ORGAN DONATION PROCESS

Before exploring the concept of an organ as a gift, it is helpful to understand the process families experience when donating organs. The UAGA and NOTA established several federal agencies to regulate the process of organ donation. NOTA authorized the creation of the Organ Procurement and Transplantation Network (OPTN), now run via a federal contract by the private nonprofit United Network for Organ Sharing (UNOS). OPTN, and thus UNOS, is tasked with establishing the network that manages how organs are allocated to recipients in the United States, i.e. the “waiting list,” and allows for distribution and sharing of organs throughout the country (Petechuk).<sup>7</sup> At a local level, Organ Procurement Organizations (OPOs) work with local hospitals and transplant centers to identify potential recipients, arrange for the surgeries to obtain the organs, and distribute the organs to hospital transplant centers for actual transplantation. OPOs are assigned to one of eleven geographic regions in the United States, and in turn these eleven regions are governed by UNOS and OPTN. Regulations exist for deceased organ donation and donation by living donors, but both follow prescribed processes designed to uphold ethical norms and protect both the donor and the potential recipients. For context, in 2016 33,610 organ transplants were performed in the United States. There were 27,630 transplants

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<sup>7</sup> Bone marrow transplants and blood transfusions are not included with solid organ transplants, and are not regulated though UNOS.

using cadaveric organs from 9,971 deceased donors. Living donor transplants, in which one organ is donated by each donor, accounted for 5,980 transplants, 18% of transplants that year.<sup>8</sup>

In the case of a deceased donor, if a patient has reached a point in which physicians no longer feel that survival is possible or in which criteria for brain death has been established, a referral is made to the local OPO. A representative from the OPO will assess the patient and if any of the patient's organs are believed to be appropriate for donation, the representative will approach the next-of-kin to offer the option of donating those organs (Fulton, Fulton and Simmons; Gortmaker et al.). Most OPOs require next-of-kin to give consent for donation even if the deceased had previously expressed a desire to be an organ donor, usually on his or her driver's license. Despite provisions in the UAGA that regards the wishes of an individual above those of next-of-kin, OPOs and hospitals are wary of not deferring to the next-of-kin due to fear of litigation (Overcast et al.; Prottas). After consent is obtained, a complicated process ensues to match the potential donor organs with potential recipients, involving complex mathematical algorithms specific to each organ, details of which are beyond the scope of this essay. With each donor, the goal is to help as many potential recipients as possible; a frequently cited fact is that one deceased donor can save as many as eight lives.<sup>9</sup> Individual transplant centers evaluate the medical history of the donor, and in sequential order of patients on the waiting list, can accept an offered organ. The OPO will arrange for the surgery to procure the organs, and various surgical teams from the transplant centers will travel to the hospital of the donor for the procurement surgery. After the surgery, the teams return to their home hospitals and perform the transplants on their patients. During this time, the family of the donor is emotionally supported by both the staff at the hospital and staff from the OPO. The family continues to participate in the care of the patient, other relatives not immediately present are given time to travel to the hospital, and everyone is given time to say goodbye.

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<sup>8</sup> Based on OPTN data as of October 16, 2017; <https://optn.transplant.hrsa.gov/data>.

<sup>9</sup> <https://optn.transplant.hrsa.gov/>, accessed 10/2/17.

However, as discussed above concerning anonymity, the identity and even location of the intended organ recipients is not shared with the family. Should either party wish to contact the other, inquiries must be coordinated through the OPO weeks or months after the actual transplant. Initial contact is at first still anonymous, usually through letters written with names and identifying information obscured. If after receiving the letters the two families wish to speak or meet, the OPO can forward the contact information to both parties, but, again, only if both families agree.<sup>10</sup>

Living donation differs from deceased organ donation in that the donor likely knows the recipient, usually a family member or other close relationship, and because the donor gives consent him or herself while alive. Although OPOs are typically not involved in the process of arranging for living donation, these transplants are also regulated by UNOS and OPTN, both to ensure that proper procedures are followed and for purposes of data collection. Any potential living donor undergoes a thorough assessment not only of his or her general health, but also his or her psychologic state to ensure that he or she understands the potential medical risks and to safeguard that no undue coercion has occurred. From the early days of organ transplantation, the medical profession has recognized both the subtle and overt pressures exerted on potential living donors by recipients, their families, and even medical professionals themselves, as they try to advocate for the ill patient who would greatly benefit from the transplant (Fellner and Schwartz; Fox and Swazey "Organ Transplantation as Gift Exchange"). To protect the donor from physician conflicts of interest, transplant centers must ensure that the physicians who evaluate and care for the donor are not involved in the care of the intended recipient. In addition, each center must assign a donor advocate to the case, usually a specially trained social worker, to look out for the interests of the donor. The donor advocate not only helps the potential donor navigate the complicated process, but is trained to know and understand a donor so that he or

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<sup>10</sup> For a fictional example of this, the 2000 movie "Return to Me" shows a heart recipient writing an anonymous thank you letter to the family of the donor, with the letter addressed only to the OPO "Organ Donor Coordinator." The letter is eventually forwarded the deceased donor's widower.

she can act as the donor's voice within the medical team and to bring up any psychosocial issues that might adversely affect the donor. The transplant will only take place if the potential donor is found to be healthy, so that medical risk is minimized, and also mentally competent to consent and avoid coercion. Usually, the donor and recipient remain in close contact throughout the process, often celebrating the event together while they simultaneously recover from surgery. This is not surprising considering that many living donors are in some way related to the recipient, either genetically or socially.<sup>11</sup>

At its most basic premise, organ transplantation is dependent upon a literal transaction of an organ from one person to another. As outlined above, in the United States the practice of organ donation has evolved to be voluntary, altruistic, and anonymous. The organ transplant community uses the construct of a "gift," and its derivative phrase the "gift of life," in an attempt to portray the priceless offering that donating organs is thought to represent. The word "gift" is ubiquitous in websites, pamphlets, and media representations designed to promote organ donation. However, referring to organ donation as the "gift of life" may be too simplistic a phrase to encompass the complicated emotional and interpersonal repercussions of donating a physical part of one's body. Deconstructing the idea of the "gift" of an organ donation can lead to critical insights into the relationship between organ donor and organ recipient. Now that we have examined the process of organ donation, we should further explore the meaning of a "gift."

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<sup>11</sup> Paired kidney exchange is a situation in which a living kidney recipient may not have a relationship with his or her donor. Some patients with end stage renal disease may have a family member or friend who is willing and able to donate, but the donor and recipient may be considered incompatible, usually due to incompatible blood types. In these situations, the patients can enter into what is termed a "paired donor exchange," so that a donor from one pair actually donates his or her kidney to an unknown recipient, and that recipient's living donor volunteer donates his or her kidney to the original recipient. In the early 2000's, this exchange typically occurred only at a local level, with both pairs being cared for by a single transplant center. However, an algorithm was developed that allowed for incompatible donor/recipient pairs to find other such pairs outside of their home program, greatly expanding how often this option is employed (Segev et al.). In these situations a kidney recipient may not know his or her actual donor, but because the transplant itself was only possible through the willingness of his or her family member or friend to donate, the celebratory aspects and the relationship with the known donor still closely resemble those seen in living donation performed between compatible donors and recipients.

## CHAPTER 2

### GIFT OR CHARITY? THE DONOR-RECIPIENT RELATIONSHIP

Standard practices in the United States relating to organ donation imply that organs should be donated voluntarily with no expectation of recompense. Here I examine Marcel Mauss's observations about gift giving to analyze whether this is the appropriate metaphor to describe organ donation. Whether this comparison is accurate depends on how we view the relationship between donor and recipient. Furthermore, the concept of organ donation promoted by the transplant community may not correspond to the wishes of the donors and recipients themselves.

#### MAUSS AND THE POTLATCH

Much of modern sociologists' understanding of the ideas of gifting and exchange can be traced to Marcel Mauss's seminal work on the topic. A French sociologist and anthropologist, Mauss published his essay *Essai sur le don: Forme et raison de l'échange dans les sociétés archaïques* in 1925 (Mauss). Mauss argues that gift giving is part of a larger societal relationship that is based on reciprocity between the gift giver and the recipient. He opens the essay with excerpts from an ancient Scandinavian poem describing the exchange of gifts in that society, followed by lengthy descriptions of how gift giving is practiced by indigenous societies of the Pacific Northwest, Polynesia, and Melanesia. One such example is the Kula rings found in the Trobriand islands. Mauss's insights concerning the Melanesians was based on the earlier work of Bronislaw Malinowski, a Polish anthropologist, who had studied the Kula ring in his book, Argonauts of the Western Pacific, originally published in 1922. Both Malinowski and Mauss described the Kula ring as a pattern of exchanges between islanders in which more-or-less equally valuable objects were exchanged in well-established paths from one tribe to another such that the



objects eventually returned to the original owner. These exchanges were less concerned with the value of the gifts as much as the social exchange between the tribes, reinforcing communal interactions and keeping peace amongst the groups.

Mauss then presents the idea of “potlatch,” a Chinook term that in its simplest definition is a gift giving feast, although the reality is much more complex and nuanced. To Native Americans of the Pacific Northwest these festivals were highly ritualized meetings held at times of cultural significance, including religious observances, marriages, funerals, building a house, and inter-tribe political negotiations. Gifts were bestowed to all who attended, but with the implicit expectation that something was given in return. A potlatch held as part of a funeral may be a way to distribute the deceased person’s possessions, or if held to celebrate a marriage may be a way for two families to exchange gifts that symbolize their new relationship. The gifts did not necessarily need to be a concrete thing, but could include the food itself, hospitality, and entertainment provided at the ceremony. Mauss perceived that establishing and maintaining hierarchy amongst the participants was an important aspect of the potlatch. For members within an individual tribe this included respecting and honoring one’s chief, and for different tribes this involved allowing equal time for each tribe to perform their ceremonial dances and songs. The gifts exchanged are also of a communal nature, as opposed to an exchange between individuals; gifts might be exchanged between tribes or small tokens might be given to all members of a particular tribe from a chief or wealthy family. There was often an element of one-upmanship in which the reciprocated gifts had escalating values leading to progressively more extravagant gifts or displays. The picture that emerges in his description is of a highly ritualized event at which the exchange of gifts and services reinforces societal relationships, both within and amongst tribes. The actual gifts themselves are less important in terms of a measurement of wealth than the relationships the exchange of the gifts represent. Mauss further observed that in order to remain in good standing in these societies, participation in these rituals was not voluntary but compulsory. Failure to participate shows

dishonor to the leaders of a tribe or tribes, and for tribes to refuse to participate with each other is akin to declaring war.

From observations of these different cultures Mauss arrived at a common set of societal obligations to give, to receive, and to reciprocate as means to develop and strengthen relationships between individuals and groups. However, he does not argue that these observations are only relevant to those societies; he also explores the legal history of exchange in ancient Roman, Hindu, and Germanic societies. To Mauss, this cycle of gift giving and receiving forms the essential bedrock of societies, and to refuse to receive a gift or to fail to reciprocate are acts equally taboo. Implicit in this structure is having a known relationship between the giver and receiver, and the ability of the receiver to reciprocate the gesture in some way. To Mauss the creation and strengthening of social relationships is the fundamental and vital aim of gift exchange.

Mauss's concept of a "gift" as an act that implies some form of recompense in kind is not what is practiced by the transplant community at large in terms of organ donation. In the United States, the convention that deceased donor organ donation is voluntary, altruistic, and anonymous is expressly at odds with Mauss's paradigm. The theoretical wall of anonymity that is erected between donor family and recipient in the case of deceased donor organ donation would seem to prevent any type of personal relationship or direct reciprocity that Mauss's concept of gift exchange requires. The altruistic nature of organ donation is also contrary to the idea of gifts strengthening rather than weakening relationships, because the lack of reciprocity renders the giver and receiver as unequal participants in the exchange: "the unreciprocated gift still makes the person who has accepted it inferior" (Mauss). Even the voluntary nature of organ donation would seem to contradict Mauss's model, although this is a more subtle distinction. Mauss presents the act of giving as a societal obligation based on maintaining preexisting relationships, rather than a voluntary act, stating that "to refuse to give . . . is to reject the

bond of alliance and commonality” (17). He sees the obligation to give as equal to the responsibilities to receive gifts and reciprocate gifts. Furthermore, he states:

. . . everything – food, women, children, property, talismans, land, labour service, priestly function, and ranks – is there for passing on, and for balancing accounts. Everything passes to and fro as if there were a constant exchange of a spiritual matter, including things and men, between clans and individuals, distributed between social ranks, the sexes, and the generations. (18)

Although organ transplantation was not a reality at the time Mauss wrote his essay in 1925, from the passage above one could extrapolate that the gift of donating organs might fit into his theory of a gift one should be obligated to give as part of a “constant exchange.” However, the obligation to donate organs would contradict the contemporary notion that donating organs must be a voluntary rather than obligatory act.

Several questions arise from trying to fit organ donation into Mauss’s construct. Mauss dismisses charitable giving as not conducive to establishing and strengthening societal relationships. Recent authors engaging his writing have questioned this approach (Laidlaw). Could organ donation fall more easily into the category of charitable giving, a gift made with no expectation of a reciprocal gift? If not, then might Mauss’s concept of gift giving nevertheless help in understanding what is taking place in the practice of organ donation?

#### ORGAN DONATION AS AN ACT OF CHARITABLE GIVING

Mauss himself appears to reject the possibility of truly charitable giving, and subsequent anthropologists have followed his lead by concentrating on the relational aspects of gift giving (Laidlaw). In his conclusion Mauss states that “the unreciprocated gift still makes the person who has accepted it inferior, particularly when it has been accepted with no thought of returning it” (83). Although Mauss’s concept does not preclude anonymous or unreciprocated gifts, he would argue that preventing a recipient from reciprocating, either by giving a gift anonymously or by refusing a reciprocal gift in kind, is

ultimately more harmful than helpful in that it undermines rather than enhances relationships. As Mary Douglas writes in her foreword to the book, “a gift that does nothing to enhance solidarity is a contradiction” (Douglas).

Nicole Gerrand, an Australian philosopher, argues that the act of organ donation is more in line with a charitable act than with a gift (Gerrand). She explores different situations in which gifts are bestowed in modern society, looking both at the reasons for giving the gift as well as the relationships between the giver and receiver. For example, she describes examples of gift giving that occur at formal occasions between people who do not know each other well, such as a wedding, with gifts that are exchanged between loved ones. Gifts exchanged on formal occasions and between people who do not already share a close relationship imply an obligation to exchange gifts that recalls Mauss’s construct of gifts that develop societal relationships. Alternatively, gifts exchanged between people who already share a close bond may have less to do with obligation than with expressing an emotion or strengthening an already established relationship. The need to reciprocate a gift may also vary depending on the situation. For example, the person who gives a gift to a young child on his or her birthday may have no expectation of a reciprocal gift. Gerrand then characterizes charitable giving, such as donating money, used clothing, or food, as being both supererogatory and anonymous. Specifically, an act of charitable giving is something that is not expected or morally necessary. So, charitable giving is by definition voluntary. Because the giver in most instances does not know the specific recipient of these gifts, usually because they are distributed through an intermediary organization, they are also anonymous. Furthermore, she emphasizes that for a gift truly to be charitable, the motivation behind giving the gift must be a desire to help an unknown person with no expectation of any type of return.

Thus, Gerrand has defined charitable giving as being voluntary, altruistic, and anonymous, leading to her conclusion that our current paradigm for deceased donor organ donation is more consistent with charitable giving, and structurally different than Mauss’s concept of gift giving. Organ

donation, per Gerrand, is not an obligatory act that includes reciprocation, although it can strengthen societal bonds. Her conclusions about charitable giving and organ donation appear to fit neatly into the current US legal concept of organ donation. As we have seen, there are laws that uphold the voluntary and altruistic nature of organ donation, and administrative precedent endorsed through UNOS encourages deceased organ donation to be anonymous, at least initially. Gerrand herself does not include living organ donation in her conclusions about charitable giving, acknowledging that the preexisting relationship most living donors and their recipients share precludes anonymity and may not be truly altruistic. Because Gerrand limits her arguments to deceased organ donation, I will similarly limit myself here.

Gerrand's association of organ donation with an altruistic act is supported by surveys of the public. A team of researchers at Brandeis University led by Helen Batten and Jeffrey Prottas surveyed both donor families and members of the lay public about their beliefs concerning donation. One study surveyed 242 families who had agreed to deceased organ donation of a loved one (Batten and Prottas), and another surveyed 750 laypersons who had not had personal experience with organ donation (Prottas and Batten). As part of their analysis, the researchers compared responses from the laypersons who stated they would agree to organ donation, 358 of the original 750 interviewees, with the donor family responses concerning their reasons for donating organs. Both groups responded that the most important reason to donate organs was to help someone else live, 86% of donor families versus 88% of laypersons. Both groups also responded that they believed functioning organs should not be wasted, 75% versus 66%. Interestingly, the two groups' responses began to differ when responding to whether donation makes "something positive come out of death," with only 60% of the general public agreeing with this reason as opposed to 86% of donor families. Similarly, when asked about the reason "relative could live on in someone else" only 41% of the general public supported this, whereas 68% of the donor families supported this. The responses for these latter reasons may have to do with the recent personal

experience of the donor families experiencing death, as opposed to the laypersons who may not have grappled with the grief associated with the loss of a loved one and were answering these questions from a theoretical perspective rather than from personal experience.

## THE DONOR PERSPECTIVE

At its core, Mauss's construct of gift giving requires a relationship between donor and recipient that is highly discouraged in the anonymous model currently practiced for deceased donation, although it is readily apparent in cases of living donation. Gerrand's model, on the other hand, seems to support the legal and administrative practices currently employed for deceased organ donation. In order to understand whether organ donation does, or should, be considered either a Maussian gift exchange or a charitable donation, it is helpful further to examine the perspectives of both donor families and recipients. For the purposes of argument, I will limit myself to deceased organ donation. Consent for donation is usually obtained from the next-of-kin, since the donor has died. Thus, it is the donor's next-of-kin who is the actual donor in this case, and it is the donor family with whom any potential relationship with the recipient might occur.

The first part of Mauss's model concerns the obligations to give to others, understood as necessary to maintain preexisting relationships that are the basis for a society. As members of society, Mauss would argue that we have a responsibility to participate fully in the exchange of goods and labor in order to maintain order; otherwise a refusal to participate is akin to refusing to be a good citizen. Within this framework, one way to interpret a family agreeing to donate organs of a deceased loved one to recipients with whom they have no direct relationship is that organ donation represents a gift given to society at large. The surveys by Prottas and Batten would seem to support this interpretation, as they found that 72% of all respondents would be willing to have their organs donated at their death (Prottas and Batten). They performed subgroup analysis showing that more highly educated persons and non-

minorities were more willing to donate, and their interpretation was that those groups identified as members of a larger community and had expectations that the community would support them if they needed help. Conversely, they argued that members of minority groups, who have historically been excluded from many of society's benefits, were less likely to see themselves as members of such a community and therefore less likely to donate (Prottas). Thus, those that see themselves as part of a community felt an obligation to donate. Donald Joralemon, a medical anthropologist, argues that a donor family's decision to donate should more correctly be viewed as akin to actions citizens might take during times of disaster or war to help others in the community or nation, emphasizing that the gift relationship of interest is not between two discrete individuals or groups but rather the relationship of a family to the broad citizenry (Joralemon). This reading of the gift relationship, that the donor family is giving to society at large rather than individual recipients, does uphold the administrative and charitable idea that organ donation should be anonymous.

The second part of Mauss's model concerns the obligation to receive. If the gift exchange is between a donor family and society at large, then this particular question is easily explained. Society at large and the medical community are eager to accept the potential organs in order to satisfy the needs of the patients with end stage diseases. The potential benefits of organ transplantation to society are beyond the scope of this essay, but include among other things increased life expectancy for the recipients, improved quality of life for both recipients and their families, and decreased money and resource utilization. In addition, the medical community at large has accepted organ transplantation as the standard of care for the treatment of certain diseases. As such, society's obligation to receive the organs in order to benefit its members with end stage diseases is readily fulfilled.

The third part of Mauss's model is the obligation to reciprocate. Continuing with the assumption that it is society that is participating in the exchange, the donor families should have a reasonable expectation of support from the medical teams and their communities. Benefits of organ

donation typically focus on psychological benefits to the donor family. The reciprocal gifts the family receives includes the various way they might receive comfort, as well as the general benefit that comes overall participation in a civilized society. But what should donor families expect in return for the donation?

After agreeing to donate the organs of a loved one, donor families are thought to experience a psychological benefit from the act of donation, because the donor families might begin the healing process more quickly and find solace in knowing that the death of their loved one offered hope and life to another patient or patients (Sharp "Organ Transplantation as a Transformative Experience: Anthropological Insights into the Restructuring of the Self"). A group of sociologists at the University of Minnesota interviewed families who had agreed to deceased organ donation on behalf of a family member (Fulton, Fulton and Simmons). In total they interviewed 35 individuals from 12 families. Family members that maintained a positive attitude towards the transplant emphasize that it was the one good thing that occurred as a result of their loved one's death. Comments included "the death was not a total loss" and "somebody profited some way." Other comments also demonstrate that the very act of making a decision to donate gave donor families a small sense of empowerment at a time when they likely felt powerless: "the idea of donation helped; it gave me something tangible to hold on to" and "if we can't save him, we can save someone else." In the surveys performed by Batten and Prottas, 79% of donor families and 81% of the general public felt that organ donation aided families in the process of grieving. Furthermore, 70% of donor families and 75% of the general public agreed that organ donation helps lessen the pain associated with the loss of a loved one (Batten and Prottas).

More concrete than feelings of good will and lessening grief is the possibility that families use the donation process to buy time with their loved one. Nursing researchers in Canada performed interviews with families of deceased organ donors and identified "buying time" as one of five thematic reasons families gave for agreeing to donation (Manuel, Solberg and MacDonald). Even when families



had accepted the ultimate outcome of their loved one, they still appreciated the extra time, even if only a few hours, that organizing and mobilizing the transplant teams allowed the family to spend with their loved one while still on life support. The authors further speculate that this added time may have also benefitted the families by allowing them the chance to relive the events that had brought them to this point and thus begin the emotional work of processing their grief. In other situations, families may have wanted to buy time because they had not quite accepted the fact that their loved one was not going to recover. One mother reported:

Well, I thought there is nothing wrong with my [child]. [Child] is just in a coma and is going to wake up anytime and tell these doctors that I am going home with Mom. It never did happen, but it gave [Child] another five hours to show that those doctors had to be wrong. It just could not be true. (Manuel, Solberg and MacDonald)

The Minnesota group also identified other families who similarly had agreed to donation because it would provide a medical evaluation by another team, a chance for a second opinion to contradict the conclusions that the family was struggling to accept as accurate (Fulton, Fulton and Simmons).

Donor families may also take comfort in being able to ascribe the good done for others with positive attributes they believed the deceased possessed (Markmann). This can take one of two forms. If an ill person who is potentially a donor was thought to be a kind, caring person in life, donating organs is a means of continuing the good works that person might have performed if his or her life had continued. One mother, interviewed by the Canadian group, described her child as “having a kind and giving nature . . . we knew that [Child] would have wanted to help other people” (Manuel, Solberg and MacDonald). In essence, it is a way to honor the person’s character and to act on their behalf in a manner the family believes is consistent with that person’s core values. Harris and his colleagues surveyed psychology students by presenting fictional clinical scenarios in which a young patient has suffered a tragedy, making them a potential organ donor, then asking whether the surviving family should or should not consent to organ donation (Harris et al.). They noted that the survey respondents were more likely to recommend donation when the fictional donor was ascribed positive attributes,

such as being “generous” or “popular,” and less likely when the donor was described negatively, such as being “a loner.” The authors interpreted the survey respondents’ attitude as assigning greater value to the organs from a person deemed as more worthy, even while permitting that these characteristics are unlikely to affect the quality of the organs themselves. An alternative interpretation is that the survey respondents were respecting what they inferred would have been the wishes of a person known to act generously in life, thus assuming that person would approve of continued acts of generosity at the time of their untimely death.

The ability to ascribe good acts to the deceased donor could also be seen as a way to redeem a person who might not have been seen as the most generous or virtuous in his or her life. This is the approach that was used for comedic effect in a video produced by Donate Life America and The Martin Agency that went viral in 2016 (<https://www.youtube.com/watch?v=qj4Z-dhZ2Z4>). The video was created as a way to encourage young men to become organ donors. A fictional character named Coleman F. Sweeney is initially portrayed going about his life behaving boorishly: he steals Halloween candy from trick-or-treaters, shoots paint balls at a neighbor’s dog, and finds a creative way to engage in public urination. In a diner we see him trying to stiff a waitress, when he has what is presumed to be a stroke. However, the waitress finds his driver’s license, on which he is a designated organ donor. The film then shows the recipients he has helped in that final act of organ donation: a teacher, a father, a veteran, even the neighbor who owns the dog he shot with paintballs. The video ends with a frame showing the words “even an asshole can save a life” before directing viewers to a website to register as an organ donor. Thus, organ donation can be a final redemptive act of an individual designated as a donor or a family who decides to donate a family member’s organs.

In the study out of Minnesota mentioned above, one of the authors’ conclusions centered around the families’ expectation of information about the organ recipients and sufficient gratitude from both the medical team and the recipients themselves; 15 of the 35 interviewees specifically wanted

more information about the recipients (Fulton, Fulton and Simmons). Each family had been sent a follow-up letter to inform them of which organs had been transplanted, although the identifying information of the recipient or recipients was not made available to them. The transplant team in these situations had attempted to maintain an anonymous and altruistic model for donation, but at least some of the families clearly believed that they were owed something more in return for the donation, that is, information about the recipient. As one mother stated, “. . . they’ve given so much and they want something back.” Their desire for information about the recipients was often tied to beliefs that if the recipient, and therefore the organ, were doing well then the donation was worthwhile and they were able to assign some positive outcome to their loss. Interestingly, several of the family members expressed that they did not necessarily want to know if the recipient, and thus organ, had not fared well:

If the patients weren’t doing well, we [the parents] wouldn’t want to know. It still gives you a little bit of hope that he didn’t die for nothing, and maybe somebody is getting some help from this. Maybe somebody else has a child that is alive on account of my son and they can live a normal life. (Fulton, Fulton and Simmons)

This quote underscores another belief that many donor families share: that their loved one lives on through the recipient or recipients. This belief is another way in which donor families are thought to find solace despite their loss (Sharp "Organ Transplantation as a Transformative Experience: Anthropological Insights into the Restructuring of the Self"). Batten and Prottas were able to show this quantitatively, in that 68% of donor families and 41% of the general public respondents agreed with the statement “relative could live on in someone else through donation” (Batten and Prottas). The studies that conducted first person interviews with family members of organ donors confirm that this idea is widespread. One father told the researchers in the Minnesota study “in a sense you think they’re still around and yet they’re not. [As long as his kidneys still function] he isn’t dead down there” (Fulton, Fulton and Simmons). Similarly, a relative told Manuel and the Canadian researchers:

The thought of parts of [Relative] going on still living – that is what helped the family to donate [Relative’s] organs. We thought it would keep [Relative] alive in somebody else. So that was basically the main reason for donating – just that [Relative’s] memory or parts of [Relative] were still alive. That was my idea of donating. (Manuel, Solberg and MacDonald)

Returning to the comments of the families from the Fulton study who wanted information about their recipients, their desire for only positive information can be interpreted as based on fear that learning the recipient or recipients had poor outcomes would be like a second death of their loved one (Fox and Swazey "Gift Exchange and Gatekeeping").

The fact that families understand organ donation as allowing their loved one to live on through someone else illustrates that families do not interpret the gift as being given to society at large, but rather to individuals. Although we cannot be certain that it did not factor into their decision to donate, the comments from these donor families do not include mentions of how the donation benefitted society and their community. Instead, donor families consistently focus on the recipients, wanting information about their individual outcomes and even wanting a personal relationship with them. Although Joralemon has argued that organ donation is similar to citizens donating time, goods, or effort during times of disaster or war, I would respectfully disagree (Joralemon). When citizens work together during times of war, they can be seen as furthering a cause, working towards a shared outcome for society. Alternatively, when volunteering after a natural disaster, such as giving to a food drive, the potential beneficiaries are numerous. When a family agrees to organ donation the emphasis is on a finite number of people. The decision involves individuals who will live on through the “gift of life,” rather than involving a cause or the community at large.

The attention donor families focus on the individual recipients places the gift of organ donation more clearly within Mauss’s construct than under the rubric of charitable giving. If individuals are the recipients, rather than a community or society, then anonymity between the donor family and recipients becomes more problematic. Anonymity prevents the reciprocity Mauss argues is necessary. In addition, trying to substitute society in place of the recipient within this relationship might explain donor families’

frustration at how little they receive in return for the donation of organs, because the reciprocal gifts are not coming from the correct source. In other words, the transplant community is substituting the relationship between donor family and society for the relationship that should be formed between the donor family and the organ recipients. If, as Mauss believed, the aim of gift exchange is to strengthen relationships, then conflating the transplant recipients with society at large may actually undermine rather than encourage bonds between members of society. By not receiving what they feel they deserve in return for donation, donor families may have less trust in the medical community and society.

#### THE RECIPIENT PERSPECTIVE

When we hear stories of organ transplantation, the assumption is that a recipient should be joyful and appreciative of the gift they have received. However, the reality is that the recipients' experiences, like those of donor families, are much more nuanced. From Mauss's perspective, the potential organ recipient enters the relationship with an obligation to receive the gift. In the case of deceased organ donation, the very fact that recipients have gone through the process to be placed on the waiting list shows their inclination to accept an organ, when and if one becomes available. The benefits one would expect to obtain from the gift, namely the opportunity to both extend life and improve quality of life, are so valuable that most potential recipients are eager and willing to accept an organ. The obvious benefit is apparent enough that it is assumed to be true and is rarely addressed in the literature.

But it is the extreme value of the gift that makes the next part of Mauss's model, the obligation to reciprocate, so problematic. The donation itself is often termed the "gift of life," and especially in situations in which the patient has end stage liver disease or end state cardiac disease, whether or not a patient receives a transplant may literally be the difference between life and death. As such, the

donation itself is frequently described as a “priceless” gift. The very fact that the gift is so valuable can render the recipient unable to reciprocate the gift. In this sense, it recalls what Mauss described as sometimes occurring during a potlatch. The gifts given between tribes or families were often used to exhibit their wealth and power. At times there would be a series of gift giving in which subsequent gifts had increasingly escalating value, until eventually one party was unable to reciprocate, thus proving the other’s dominance. When a gift as valuable as an organ donation is given, it sets up a power differential from which the recipient may feel helpless to reciprocate.

Renee Fox and Judith Swazey, American sociologists and bioethicists, have termed this sense of guilt of not being able to reciprocate as the “tyranny of the gift,” a phenomenon that is in line with the Maussian principle of the obligation to reciprocate a gift (Fox and Swazey "Organ Transplantation as Gift Exchange"). In terms of deceased organ donation, several problems present themselves. First, in addition to the sheer impossibility of repaying such a priceless gift, the anonymity associated with organ donation at the very least impedes and at worst completely prevents a recipient from even offering thanks to the family who decided to donate. Mechanisms do exist that allow the recipient and donor families to communicate, usually through anonymous letters screened by OPO staff, but these methods can be delayed several months after the transplant itself and may feel inadequate to both the donor and the recipient. To put it in the perspective of the potlatch, even if the recipient does succeed in offering thanks, the value of the original gift so surpasses the act of offering thanks as to continually render the donor as superior to the recipient. Second, the power differential established may lead to the donor family feeling entitled to be part of the recipient’s life. When a donor family does want to maintain close contact, a recipient may feel such a deep obligation that they feel helpless to prevent such contact or involvement, even if it is not desired and feels intrusive. Because the transplant typically occurs at a time of great stress or need for the recipient, especially if a recipient is potentially facing death in the absence of a transplant, the feelings of guilt and obligation may not be experienced at the time of the

transplant and may not be appreciated until long afterwards during the recovery period. It is this phenomenon from which OPOs and transplant professionals are trying to protect recipients with the policies of anonymity (Sharp "Public Encounters as Subversive Acts"; Sharp "Organ Transplantation as a Transformative Experience: Anthropological Insights into the Restructuring of the Self").

As mentioned earlier, transplant professionals are wary of encouraging donor families to think of their loved one as living on in recipients because of the pressure this might place on a recipient, especially as they are recovering from a stressful transplant surgery. The recipient's sense of indebtedness for such a valuable gift may lead to the recipient acquiescing to whatever level of intimacy the donor family desires. Fox and Swazey discuss a situation in which the father who donated his son's organs, including the heart, tells the father of the girl who received the heart "we've always wanted a little girl, so now we're going to have her and share her with you" (Fox and Swazey "Gift Exchange and Gatekeeping"). On first reading this statement, it certainly seems presumptuous and intrusive – the donor father is assuming that he and his family have some claim over the recipient and her family. Lesley Sharp, an American medical anthropologist, terms the phenomenon in which donor families assume a close bond with the recipient as "fictive kinship" (Sharp "Public Encounters as Subversive Acts"). She acknowledges that transplant professionals might try to protect both donor and recipient families from unwanted intrusion from another family who are, in reality, strangers.

Sharp cautions that this attitude might be a paternalistic response that neither the donor families nor the recipients actually desire. Quoting a family member speaking in regards to donor and recipient families meeting, "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" (Healy). Examples of donor families and recipients meeting are plentiful, and the meetings can lead to long lasting, fulfilling relationships in rare circumstances. Amy Loceiro was killed in 1993 during the well-publicized Long Island Railroad shooting, and her parents subsequently agreed to organ donation. Her father, Jack, has publicly discussed the

relationships he and his wife have developed with several of the recipients of Amy's organs. Of particular note, the recipient of Amy's heart is especially close to the Loceiros, even sending flowers to Amy's mother on Mother's Day (Healy). Sharp recounts another example in which a mother donated her son's organs, and the recipient of her son's heart maintains a close relationship with the mother many years after the transplant. The heart recipient even call's the donor's mother "mom," despite the fact that the recipient is several years older than the mother. Together, they sought out the recipient of one of the son's kidneys, and now the kidney recipient and heart recipient consider themselves siblings (Sharp "Public Encounters as Subversive Acts").

Sharp also presents examples in which either the donor family or the recipient family is not so enthusiastic about a new relationship with fictive kin. She recounts the experience of a man who received a double lung transplant. The widow of the donor had reached out to him, and through the OPO contacts were established. The recipient himself states "she thinks that her husband lives on in me; but I feel uncomfortable about that" (Sharp "Public Encounters as Subversive Acts"). Yet, the recipient and his wife continue to correspond with the widow, despite his discomfort. Sharp does not delve further into why the lung recipient continues the relationship in spite of his reluctance. But she mentions that he recounts his wife's belief that one must always write back when someone sends a letter, thus implying that his continued participation in their correspondence is as much driven by a sense of obligation than by a true sense of finding joy in their relationship.

## LIVING DONATION

Up to this point, I have been focusing on deceased organ donation. However, the effect of organ donation on living donors and recipients has also been well documented, and the beliefs and attitudes of living organ donation recipients have many similarities with the recipients of deceased organ donations. As illustrated above, deceased organ donation cannot be so easily categorized into



either Mauss's paradigm of gift exchange or charitable giving. In contrast, the fact that living donation most typically occurs between two persons who have an already established relationship means that Mauss's model is the most logical lens through which to view this act. The preexisting interpersonal relationship between the organ donor and recipient can be the basis for the obligation to give and the obligation to receive. In fact, in the 1970's and 1980's kidney transplant teams would almost exclusively consider genetically related donors, being suspicious of the motives of potential unrelated donors, even when they had clearly established social bonds such as marriage or adoption (Fox and Swazey "Organ Transplantation as Gift Exchange"). Historically, the medical profession grappled with how to justify the risk inherent in living organ donation, and knowing that the donor and recipient had a well-established interpersonal relationship provided a means to understand the donor's wish to donate. Over the ensuing decades, as both immunosuppression medications and the understanding of mechanisms of rejection have improved, teams no longer exclude non-genetically related donors if the social relationship is clearly established. Furthermore, the practice of allowing for living donation from a non-directed donor has become an accepted practice.

Most family members who volunteer as a donor feel the obligation to give very strongly. Like any situation in which a loved one is in danger, these donors want to do whatever possible, even if it means putting themselves in harm's way. Fox and Swazey recount the case of one mother of nine children who felt very strongly that she wanted to donate her kidney to her son with end stage renal disease. The medical team was initially reluctant to approve of the mother as a donor, fearing the implications to the family as a whole since she was the main caregiver for the eight other children. However, the mother "feels that it's the same thing as running into a burning building to save her son," and the team did eventually agree to proceed (Fox and Swazey "Gift Exchange and Gatekeeping"). Surveys have shown that people are more willing to act as a living organ donor if the preexisting

relationship is stronger, with there being a higher likelihood of donating if the intended recipient is a sibling or child of the donor (Shanteau and Skowronski).

The recipient's obligation to accept the gift may be confounded by other considerations. Potential recipients of a living organ donation may experience stress and reluctance to accept the donation due to concern over the risk the donor is taking, usually a family member or close friend. Additionally, the prospect of feeling guilt for not being able to repay such a gift may also affect a potential recipient's willingness to accept an organ from a loved one. The basis for both of these fears can be understood as not wanting to alter the current relationship by creating a power imbalance. If the gift of organ donation is truly priceless, then accepting the gift would mean acknowledging that the recipient is permanently indebted to the donor. Yosuke Shimazono, a Japanese medical anthropologist, interviewed Filipino living donor kidney recipients to understand how this act might fit into Mauss's paradigm (Shimazono). In one family, an older sister with end stage renal disease received a kidney donated by her younger brother. Through interviews she told of her initial reluctance to accept the donation because of she feared a medical complication and because she feared he would have difficulty maintaining employment, although she did eventually proceed with the transplant. Fortunately, both the donor and recipient recovered from the surgery, but the brother did indeed lose his employment. The recipient expressed much guilt over this, and gave him money whenever she could. She states, "You feel guilty because you cannot provide what he needs. You always have in mind that he saved you" (Shimazono). This case, then, also illustrates the difficulty in reciprocating the gift. Even in the absence of anonymity, the "tyranny of the gift" remains. Living donors feel an equal sense of inability to repay the debt as do recipients of deceased organ transplants. The tremendous worth of the donated organ in terms of potentially changing the recipient's life can make the subsequent feelings of indebtedness a burden to the recipient that can outweigh the potential health benefits brought about by the organ transplant.

Living organ donation is an emotional stressor for both the donor and recipient. Like any stressful event, family members may resort to well-established patterns and behaviors, both beneficial and maladaptive. Fox and Swazey note:

It becomes clear that the prospect of live organ donation creates a situation that lays bare the microdynamics of entire families. The life-or-death circumstances that surround it and the extraordinary gift it entails bring to the surface the structural strengths and weaknesses of a family and the collective life history in which they have been played out. (Fox and Swazey "Gift Exchange and Gatekeeping")

Despite good intentions, relationships may suffer irrevocable harm after living donation. As one recipient who received her sister's kidney notes:

. . . the donor is lured into a kind of smugness in the face of never-ending awe for the courage of his contribution, and the recipient is forever frustrated by trying to find an adequate response. In my case, while my sister continues to live a productive and reasonably healthy life, my "gift of life" was very much at the expense of a previously close relationship . . . (Fox and Swazey "Organ Transplantation as Gift Exchange")

As with deceased donor transplantation, the recipient may not understand the implications of accepting such a gift at the time of the transplant due to the immediacy of his or her health concerns. It may only be after the donor and recipient have recovered from surgery that the consequences of donation become apparent.

#### MAUSSIAN OR CHARITABLE GIVING?

Organ donation does not fit easily into either Mauss's construct of a gift or a charitable giving model. As mentioned above, the legal and administrative position would categorize organ donation as more of a charitable gift, insofar as it is designed to be voluntary, altruistic, and anonymous. In contrast, Mauss's model focuses on the obligation to give, the obligation to accept a gift, and the obligation to reciprocate, all with the purpose of strengthening relationships. But the experiences and expressed wishes of families of deceased donors clearly illustrate that donating a loved one's organs is not a purely anonymous, altruistic act; these donor families do expect something in return. And the common thread

of what the donor families desire almost always leads back to developing new and maintaining preexisting relationships. In this sense, the donor families' expectations seem to be more consistent with Mauss's model than within the mode of charitable giving, although this is still not a perfect model to explain the complexities of organ donation.

The stories told to researchers do give us insight into the gift exchange relationship. However, works of literature offer a way to explore these relationships free from the constraints of established norms of behavior -- both the expectations individuals may feel and the standard of care that professionals must maintain. In the next chapter I will explore what happens when a donor family feels let down by the system that initially insists on anonymity and charity as the model for organ donation. The short story "Whither Thou Goest" by Richard Selzer offers an opportunity to examine the ideas of voluntariness of donation and the implications of anonymous donation. Next, John Irving's novel The Fourth Hand presents an opportunity to explore a situation in which the current norms of organ donation, specifically anonymity and pure altruism, are not imposed. In placing the story outside of current ethical norms Irving allows us to see the possibilities that organ donation might provide to both donors and recipients. The world he creates through fiction may allow readers to reimagine our current construct for donating organs.

## CHAPTER THREE

### A DONOR'S FRUSTRATION IN RICHARD SELZER'S "WHITHER THOU GOEST"

Richard Selzer was a practicing general surgeon at Yale University when he began writing short stories, eventually branching out to novellas, plays, and novels. His first career provided the material for his second career, as he most often wrote about illness, surgery, and death. Although he practiced as a general surgeon, his fictional works included other areas of medicine, such as pediatric plastic surgery (in "Imelda") and the AIDS epidemic (in "A Question of Mercy"). He broached transplant surgery in his short story "Whither Thou Goest," about a widow who searches for the man who was the recipient of her late husband's heart. The story was originally published under the title "Follow Your Heart" in the September, 1990, issue of *Redbook* magazine, but was later republished in several of his collections of short stories (Selzer). Through Hannah's experience donating her husband's organs, Selzer explores the aftermath of organ donation for surviving family members, and allows us to examine what occurs when organ donation is not the positive experience that is presented in narratives used to promote organ donation.

#### THE DONATION

The story begins with the phrase "brain-dead," spoken by an unnamed doctor to Hannah Owens. Hannah's husband, Sam, suffered a gunshot to the head, an event we later learn occurred when a stranger hijacked his truck as Sam was helping an elderly woman change a flat tire on the side of the road. The words are vivid, blunt, and shocking, but they succeed in quickly bringing the reader into Hannah's frame of mind. Hannah is experiencing the unexpected loss of her husband, who was only 33 years old and healthy, a man who should have had many more years to live with Hannah. We learn a few sentences later that Sam had already been in a coma for three weeks when the doctor is speaking

to her, but, even after three weeks the shock of losing a husband through a random act of violence is overwhelming. The doctor pleads with Hannah, “I’m asking you to let us put an end to it . . . there is just no sense in prolonging a misfortune” (1), implying that Hannah has had difficulty in accepting the outcome. The doctor then puts the request to Hannah:

“But before we do that, we would like your permission to harvest Sam’s organs for transplantation.”

“Harvest?” said Hannah. “Like the gathering in of wheat?”

“Yes,” said the doctor. “That is what we call it when we take the organs. It is for a good cause. That way your husband will live on. He will not really have died. . . .”

“Dead is dead,” said Hannah. (1)

Hannah does give permission for organ donation, and one week after Sam’s death she receives a letter thanking her and listing seven recipients of Sam’s organs by gender, city, and organ received.

From my perspective as a transplant professional in 2017, there are several aspects of this discussion between Sam’s doctor and Hannah that are disturbing. However, the story was published in 1990, and some of the troubling aspects do reflect the common practice of transplant professionals at the time of publication. For instance, the word “harvest” has fallen out of favor for precisely the reason Hannah points out in the story – it is associated with agriculture, not medical care. Referring to a patient with a term that is more commonly associated with crops is now seen as disrespectful to the patient and his or her family who is grieving. Major journals in the field of transplantation, for instance the *American Journal of Transplantation*, specifically instruct authors that the words “harvest” and “retrieval” are no longer acceptable.<sup>12</sup> OPTN provides a glossary for terms associated with transplantation, and in today’s accepted terminology a surgeon will “recover” or “procure” the organs,

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<sup>12</sup> [http://onlinelibrary.wiley.com/store/10.1111/\(ISSN\)1600-6143/asset/homepages/AJT\\_Instructions\\_to\\_Authors.pdf?v=1&s=c007a0b893128cd142b62027102f7eadfe2b50fd&isAguDoi=false](http://onlinelibrary.wiley.com/store/10.1111/(ISSN)1600-6143/asset/homepages/AJT_Instructions_to_Authors.pdf?v=1&s=c007a0b893128cd142b62027102f7eadfe2b50fd&isAguDoi=false), accessed November 3, 2017

and the surgical procedure is referred to as either “recovery” or “procurement.”<sup>13</sup> These terms are thought better to convey that organ donation is a reputable procedure.<sup>14, 15</sup>

As a writer Selzer is crafting a short story, a literary format that must concisely and quickly build a world inhabited by characters that readers can recognize and to which readers may relate. Thus, he may have taken shortcuts for the sake of brevity, but these should not necessarily be interpreted as representing the typical practice performed in hospitals today. The introductory scene shows Sam’s doctor asking for consent from Hannah to procure his organs. By today’s standards, however, there are two things that the doctor and the team should have done, both to help Hannah come to terms with Sam’s death and to improve the chance that she would agree to donation. First, it has been shown that a practice known as “decoupling” increases the likelihood of donation. That is, the conversation about the death of a family member should be a separate conversation from the request to donate organs (Gortmaker et al.). Not only do family members sometimes have difficulty understanding that brain death is actual death, but they also may have such intense feelings of grief that making the request in the first few minutes after hearing the news may not allow the family to give sufficient consideration to organ donation. Second, the request to donate organs is usually made by a member of the OPO, sometimes called an in-house coordinator since the OPO representative will travel to the hospital to speak to the family in person. This in-house coordinator can often better explain the process of organ donation to families, since the patient’s personal physician may not be familiar with the process. Also, separating the roles of informing the family of the patient’s death from the role of discussing organ

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<sup>13</sup> <https://optn.transplant.hrsa.gov/resources/glossary>, accessed November 3, 2017

<sup>14</sup> Interestingly, the fields of bone marrow transplantation and stem cell transplantation continue to use the term harvest when discussing obtaining these cells and tissues. In these cases, tissues and cells are often removed from living patients, and the process of includes searching through blood or marrow to identify the stem cells of interest that are scattered throughout the other non-stem cells. In this sense, the word “harvest” may be more appropriate than when used to describe organ donation.

<sup>15</sup> Similar to use of the word harvest falling out of favor, the term “life support” is also discouraged. Once brain death has occurred, referring to the ventilator or other machines as “life support” is thought to potentially confuse families since they may interpret “life support” to mean their loved one is still living. Instead, the terms “machine assisted” or “ventilatory support” are preferred.

donation removes the potential for conflict of interest of the physician who has been caring for the patient (Fox and Swazey "Gift Exchange and Gatekeeping"). Both the practice of decoupling the conversations and the use of an in-house coordinator from the OPO to speak to families were developed to better address the emotional needs of the family as they process their grief, but they had the added benefit of resulting in higher donation rates (Gortmaker et al.; Salim et al.).

Setting aside these differences from current practice, it is helpful to examine this opening scene from the perspective of the person being asked to consent to donate. Obviously, the organs are recovered for donation. But there are multiple clues in the scene that point to how conflicted the decision to donate was for Hannah. Even before the doctor has mentioned organ donation, he sits across from her and takes her hands in his:

Hannah submitted to what under any other circumstances she might have considered presumption, submitted because she thought she ought to. It was expected of her. The formality of the occasion and all. (1)

The language in this paragraph illustrates how Hannah's behavior was guided more by expectations about how to act in such a situation, and less about what she was truly feeling in that moment. She acquiesces to the doctor touching her, even though she would normally have found such contact unpleasant, because she is playing the role of grieving wife. By submitting to his touch, she is also reinforcing what she sees as a power imbalance between herself and the doctor. Later when she sees his shoes, she "noticed that he was wearing oxblood wing-tip shoes of a large size. They were the shoes of power" (2). The language of submission and power reinforce that Hannah may not have felt empowered to say no to the doctor's request. The sense of powerlessness she feels and believing that certain behavior was expected of her could both be inferred as leading to her yielding passively to the request for organ donation rather than actively agreeing to donation. Selzer leaves the question of whether or not Hannah truly gave consent open to interpretation by not showing us the portion of the discussion in which she explicitly agrees to proceed. Instead, after Selzer shows us Hannah noticing the



“shoes of power,” the prose immediately transitions to one week later when Hannah is reading the letter concerning how the organs were allocated.

The Uniform Anatomical Gift Act established that an individual could designate his or her wishes concerning organ donation after death or the decision would fall to the next of kin in the absence of any such direction. A case could be made that the voluntariness of organ donation in both living and deceased donor transplantation may not be as certain as the legal framework would imply (Fox and Swazey "Gift Exchange and Gatekeeping"). Due to the preexisting relationships between living donors and their designated recipients, the ability to make a decision free from any pressures from the intended recipient or other families is recognized to be potentially fraught. However, in the case of deceased organ donation the families can experience similar pressures. The shorter time course between when the possibility arises and when the decision needs to be made is much shorter in the case of deceased donation, whereas a living donor may have weeks or months to consider his or her options. Upon listening to families after donation, Fulton and her colleagues recounted one mother who described the pressure she felt when speaking to the physician who asked them to donate her child's organs:

And then he comes with this sheet of paper and all these other things are mentioned and at the time we were really pressured into it, you know, 'Hurry up and sign this,' without really having time to talk it over. (Fulton, Fulton and Simmons)

To the families of potential deceased donors, members of the medical team may appear overly eager to acquire consent. In Fulton's study, several family members described the physicians making the request for organ donation as "greedy" or "pushy" (Fulton, Fulton and Simmons). Others have noted that families may feel a moral imperative to agree to donation, either due to their religious beliefs or a belief that society expects the donation (Fox and Swazey "Gift Exchange and Gatekeeping"). The processes described earlier, to have a specially trained in-house coordinator approach a family for donation and to decouple discussions about death and donation, have developed and evolved over the last several

decades to protect the families of potential donors from feeling undue pressure. Although simply protecting the families from undue pressure should be a worthwhile goal in and of itself, that they had the added benefit of increasing donation rates ensured that these practices would come to be considered standard of care.

By showing Hannah's discomfort, Selzer demonstrates to readers how a family member might feel pressured to consent to donation. Later in the story it becomes clear that Hannah experiences distress at the thought of Sam's organs living through others. She struggles to define herself as a widow because she cannot come to terms with the fact that Sam is truly dead:

But widowhood, bleak as it might be, seemed preferable by a whole lot to the not-here, not-there condition into which she had been thrust by the "miracle of modern science." At least if you husband were all dead you could one day get over it and go on with your life. But this! This state of bafflement. (4)

The passive tense in the phrase "she had been thrust" underscores both her initial reluctance to donate and her feelings of helplessness after the donation has occurred. Not only is the phrase in passive tense, but the word "thrust" implies a violent use of force on her. Later, Hannah thinks of doctors in terms of people who act violently without thinking or consulting others, even if they try to conceal the violence through less objectionable words:

They simply do what they want to anyway, without really thinking. Doctors, she decided, don't think. They just *do*, and cover it all up with language. *Harvest. Transplantation.* The soft words of husbandry and the soil. Even they cannot bear to speak the real names of their deeds – dismemberment, evisceration. (4)

Whether or not the doctor felt that Hannah had freely consented at the time of the request, Hannah herself clearly believes that she was coerced to do so. In her mind, the organ donation from Sam would have occurred with or without her consent.

Through Hannah, Selzer allows the reader to see the consequences of deceased donor organ donation when the family is not comfortable with the decision. With this example he appears to be supporting the basic tenets of the UAGA, because although many donor families will in retrospect view

organ donation as a positive act, there are some families who will not (Fulton, Fulton and Simmons). Selzer appears to be arguing that the transplant community and society at large should continue to uphold the idea of voluntary donation. This is in contradiction to a system of presumed consent that is the standard in several European countries. In a system of presumed consent, medical professionals may procure organs from any deceased person in whom the organs are considered suitable for transplantation. If an individual or family have some objection to organ donation, it is their responsibility to raise the objection. In other words, the patient or family must “opt out,” as opposed to the voluntary system practiced in the United States, in which patients or family must “opt in” (Caplan; Dukeminier, B and Sanders). Some proponents have argued for adopting a system of presumed consent in the United States. Through Hannah’s story, Selzer raises the argument against presumed consent, although obliquely rather than explicitly. Hannah felt that she was not empowered to prevent the donation, and the repercussions continue to haunt her for years. Surveys of families who agreed to donation of organs of a deceased loved one and members of the general public agree with this conclusion: only 14% of donor families and 22% of the general public agreed with a statement that a law should be passed that presumes consent for donation (Batten and Prottas).

## THE AFTERMATH

Hannah’s puzzlement about whether Sam was truly dead or not speaks to the commonly held belief of donor families that donors live on in the recipients of their organs. To Hannah the crux of the issue is whether or not Sam is truly dead if the multiple recipients are still living, and therefore whether or not she is truly a widow. She argues with her cousin, Ivy, a born-again Christian, about the concept of death and the day of resurrection as it concerns Sam:

What about Samuel Owen on your resurrection day? Here he is scattered all over Texas, breathing in Fort Worth, urinating in Dallas *and* Galveston, digesting or whatever it is the liver does in Abilene. They going to put him back together again when the day comes, or is it to the recipients belong the spoils? (5)

Hannah later has a dream in which she envisions two exam tables, one with Sam and one with a faceless stranger. A surgeon is present, taking Sam's heart and placing it into the other man's empty chest.

After this dream Hannah decides that if she can just listen to Sam's heart, she would be able to move on with her life. She embarks on a process of finding out the heart recipient's name and address, then contacts him to request a meeting to listen to the heart.

The belief that the donor somehow lives on in the recipient or recipients is a common one, as evidenced by the survey by Batten and Prottas in which 68% of donor families believed this to be true (Batten and Prottas). First person interviews with donor family members reinforce this finding (Manuel, Solberg and MacDonald; Fulton, Fulton and Simmons). In fact, this narrative is often used as a method to promote donation when speaking to families of potential donors (Sharp "Organ Transplantation as a Transformative Experience: Anthropological Insights into the Restructuring of the Self"). Even in the current story the doctor employs this argument, saying to Hannah, "That way your husband will live on. He will not have really died . . ." (1). In this story, it is this idea that fuels Hannah's confusion and anger, although other families gain solace from that thought. Families that find solace in this idea express that thinking of their loved one as living on through the recipient is a way for the deceased's memory to remain alive (Manuel, Solberg and MacDonald). In addition, some families view the organ or organs as retaining some small part, some essence of the donor's soul that is then somehow transferred to the recipient (Sharp "Memory Work: Public and Private Representations of Suffering, Loss, and Redemption"). However, Hannah's struggle appears to be a literal interpretation of whether Sam is truly dead if his organs continue to function.

Hannah's difficulty with this idea of Sam's continued existence stems in part from the fact that organs themselves cannot be easily categorized as simple objects. Donating an organ is different from donating used clothing to a local charity. Both can be seen as charitable acts aimed at helping others in need, but the fact that the entity given is an organ as opposed to an inanimate object imbues the gift

with additional meaning. Clothing can certainly express some aspect of one's personality, but a vital organ that is necessary for one's wellbeing is even more intricately entwined in one's idea of self. Swedish philosopher Frank Svenaeus argues that the "body belongs to a person in a stronger and more primordial sense than a personal belonging such as a car or a house" (Svenaeus). He writes about organ transplantation through the perspective of phenomenology, an approach to analytical questions that focuses on the lived experience. A phenomenological perspective maintains that the body and its parts can be both objects that we own as well as aspects integral to our identity because of the experience of living through those parts (Svenaeus; Zeiler). He categorizes any tissue or organ that has been removed from a person, alive or deceased, as an exiled body part, which he refers to as a *subject*, a combination of the words subject and object. Subjects are thought to be actors and objects are the things that are acted upon. Thus, an organ can be an object that is donated from one subject to another person, but because of an organ's role in the lived experience of a person, an organ can also be viewed as an integral part of a subject that allows for that subject's existence.

Svenaeus makes a further distinction between *strong-identity-bearing subjects*, or *SIBS*, and *weak-identity-bearing subjects*, or *WIBS*. *SIBS* would include organs such as the heart, face, and hand -- organs that are integral to an individual's identity. A face is a literal projection of a person to the world, and as such is intimately associated with one's identity. A heart, on the other hand, is endowed with symbolic meaning as the seat of the soul and emotion. Tissues such as hair and fingernails are *WIBS* because their absence is typically a temporary problem. When lost or cut, they will be replaced as new hair and fingernails grow, and therefore they do not contribute to our lived experience in the world in the same manner. Kidneys and livers, although not replaceable in the same way as hair, still may not reach the same significance in terms of self-identity as a heart or face might. When Hannah decides that she needs to seek out one of Sam's recipients, she focuses on the heart because a heart is a *SIBS*:

The kidneys, liver, and lungs, she decided, were inaccessible – hidden away in the deepest recesses of the bodies of those who had received them. How could she get to them? And the

corneas just didn't seem right. She didn't think she could relate to a cornea. That left the heart. A heart can be listened to. A heart can be felt. (9)

In addition to the symbolism of the heart as the seat of Sam's soul, it also represents a potential lived experience for Hannah: something she can hear and feel herself.

#### THE SEARCH FOR THE HEART

Hannah is able to locate the recipient of Sam's heart, and she begins a correspondence with him requesting a visit. It should be noted that Hannah employs subterfuge to do so, using a forged letter from an insurance company to gain access to the recipient's medical records, including his name and address. These methods are obviously intrusive and dishonest, but also illegal. The currently accepted methods for a donor family to approach a recipient anonymously using the OPO as a mediator might not have been uniformly practiced in the 1980's when Selzer wrote the story, or he may have believed that the methods Hannah resorts to are illustrative of her obsessive need to find the recipient. In any event, the recipient, Henry Pope, and his wife, Inez, do not want to meet Hannah. Henry and Inez initially try to refuse Hannah through polite hints: waiting weeks to respond to Hannah's first letter, having Inez write the letter instead of Henry himself, and questioning in writing how Hannah obtained their contact information, since they had assumed the information was private. Hannah is persistent, so much so that subsequent letters from the Popes threaten legal action if Hannah does not stop.

In separate letters, Henry and Inez have both clearly articulated that they do not want any further relationship with Hannah. But Hannah feels entitled to visit, as if she still has some claim of ownership on the heart. She states as much in one of her letters to Henry:

You, Mr. Pope, got the heart, or more exactly, *my* heart, as under the law, I had become the owner of my husband's entire body at the time that he became "brain-dead." Don't worry – I don't want it back. But I do ask you to let me come to Avery for one hour to listen to your heart. (14)

In a subsequent letter she reiterates this point of view: “I was the owner of the heart. It was mine to give” (16). Hannah has plainly stated that the heart was hers to bestow, and she is now articulating that she feels she is owed something in return for donating it. In essence, Hannah and the Popes are in a potlatch. Hannah believes that the Popes have an obligation to reciprocate the gift and honor her request to visit, and until they do so we could interpret Hannah as having the upper hand in this gift exchange. But the Popes feel equally as strongly that they do not want further interaction with Hannah, thus attempting to reject the construct of a potlatch with its obligation to reciprocate. Selzer writes the story from Hannah’s point of view, such that our only glimpses into Henry’s or Inez’ perspectives come from the short letters. In one letter, Inez describes the request to meet as “a little on the bizarre side” (13). The use of the word “bizarre” is an attempt by Inez to regain power in the relationship over Hannah by dismissing her request as outside the norm.

Henry, unlike his wife, appears to feel the sense of obligation to reciprocate, such that he may be feeling what Fox and Swazey refer to as the “tyranny of the gift” (Fox and Swazey "Organ Transplantation as Gift Exchange"). In one of his letters he states, “ever since I got your first letter, I’ve been feeling awful. Like ungrateful or something” (14). He feels grateful to have received the transplant, yet his reluctance to comply with Hannah’s request makes him uncomfortable in ways he cannot or is unwilling clearly to articulate. Although not explicitly expressed, we as readers do not doubt that the feelings Henry is experiencing are negative rather than positive, transforming the experience of the transplant from what was a welcomed, lifesaving event into an anxiety inducing obligation to Hannah years later. The inability to reciprocate such a valuable gift is weighing on Henry, and this may be why he does eventually, although reluctantly, agree to the visit with Hannah. However, he does so in secret without his wife’s knowledge, instructing her to visit while Inez is out of town visiting her parents. Keeping the meeting secret further underscores the inner conflict he is experiencing, the strong pull of obligation he feels juxtaposed against the desire to maintain the

anonymity his wife feels is necessary. That Henry does decide to act against his wife's wishes demonstrates the strong influence the sense of obligation has over his actions.

Interestingly, Hannah's insistence to meet Henry despite the Popes' refusals is the only way in which Selzer portrays Hannah as potentially unsympathetic. No reader would disagree that the unexpected loss of her husband engenders sympathy for her plight. Even if the reader does not agree with Hannah's belief that Sam lives on through the organs, the reader can still relate to the profound sense of grief that underlies her thoughts and actions. But in pressuring the Popes so persistently, Hannah skirts the line between zealously standing up for herself and harassing the Popes. The discrepancy between Hannah's strong desire to meet and the Popes' equally strong desire not to do so demonstrates that donor families and recipients may have contradictory desires in terms of meeting or forming relationships, no matter how grateful the recipient may feel. Even though Henry does eventually comply with Hannah's request, Henry's acquiescence to her demand can be interpreted as being driven by the "tyranny of the gift" more so than an underlying acknowledgement that the demand is reasonable.

## THE MEETING

When Hannah and Henry do finally meet, they both initially exhibit signs of being nervous. Hannah fears she will be so distracted by her thoughts and emotions that she travels by bus to Henry's town rather than drive by car. When she arrives, she finds that Henry has dimmed all the lights and drawn all the shades in his home from fear that they will be discovered. As Henry prepares to let Hannah listen to his chest, he remains detached, treating this like a clinical visit. Selzer even describes him lying down "as though he were still a patient at the hospital awaiting some painful procedure" (20). On the other hand, Hannah is instantly captivated by the sound of the heart:

Oh, it was Samuel's heart, all right. She knew the minute she heard it. She could have picked it out of a thousand. It wasn't true that you couldn't tell one heart from another by the sound



of it. This one was Sam's. Hadn't she listened to it just this way often enough? When they were lying in bed? (20)

As Henry tries to remain indifferent and unemotional during the visit, Hannah is overwhelmed by feelings of calm and happiness, brought about by her certainty that she is experiencing the heart of her husband once more. Their approaches to this meeting are on opposite ends of the spectrum between purely objectifying the organ versus viewing the heart subjectively as a *SIBS*. These divergent approaches of Henry and Hannah are emblematic of the varying responses both donor families and recipients may feel as they navigate the process of donating organs or undergoing transplantation.

The conflict between objectifying and personalizing organs has been studied by Lesley Sharp, an American anthropologist (Sharp "Organ Transplantation as a Transformative Experience: Anthropological Insights into the Restructuring of the Self"). After years of observing patients and professionals, she describes situations in which transplant professionals, donor families, and recipients all participate in both personalizing and objectifying organs. On the one hand, she argues that the language surrounding donation often personalizes the organs, encouraging families to donate by referring to donation as the "gift of life," emphasizing the great value and preciousness of such a gift, and allowing their loved ones to live on through the act of donation. Yet recipients are encouraged to think of the organ as an object, as a replacement part for an organ that no longer functions properly. Both donor families and recipients may reject these prescribed narratives. Sharp observes that recipients are usually able to objectify the organ, but that there are instances of recipients ascribing meaning to the organ beyond its function within the body. For instance, she describes the common practice of recipients treating the day of their transplant similar to a birthday, complete with a party and cake, as if they have been reborn as a new person. In addition, some recipients describe acquiring what they believe are characteristics of the donor, even if they have no first-hand information about the donor. Some recipients even suffer psychological distress trying to understand what it means to have an organ from another human living within their body, a situation that can lead to concerns over self-

identity. Similarly, the experience of donor families viewing recipients as new members of their family, referred to as “fictive kinship,” is based on personification of the organ as an integral part of their loved one. The idea of fictive kinship can form the basis of new relationships between donor families and recipients, despite these relationships being discouraged.

In the present story, Henry appears able to objectify the organ, although we do not have nearly as complete a picture of his inner thoughts as we do Hannah’s. Henry and Inez’ reluctance to establish a relationship with Hannah may stem from a belief that the heart is merely an object, valuable for its ability to pump blood but not endowed with other characteristics. However, their insistence in several letters that meeting Hannah would not be good or wise hints at some emotional turmoil that they do not want to examine or uncover. Selzer provides us with more insight into Hannah’s thoughts and motivations. She tries to objectify the organs but cannot bring herself to do so. Early in the story she refers to Samuel’s body buried in the cemetery as “the parts that nobody needed” and says Samuel himself “scattered all over Texas” (4). Yet the entire quest to find and listen to Samuel’s heart, to hear it and feel it once more, underlies how Hannah has imbued the heart with meaning well beyond its physiologic function. The character of Hannah is a personification of the conflict described by Sharp, a person struggling with how to reconcile the objective nature of an organ and the subjective experience it represents to both herself and her late husband.

The question Hannah seems to be asking at the beginning of the story is not clearly answered by the end. Initially, Hannah’s conflict appears to center on the fact that she has difficulty reconciling whether Samuel is alive or dead, since his organs continue to live within several recipients. In the hospital she tells the doctor that “dead is dead” (2), but three years later she “had been living this gray place, unable to grieve or get on with her life because she no longer knew who or even what she was” (9). She decides that if she can “listen once more to the heart, she would be healed” (7), but it is not clear whether this would definitively answer her question about whether she is a widow or not. When

she does meet Henry and listens to the heart, she instantly recognizes it as Samuel's, and this leads her to find comfort. As she leaves Henry's house, she has "the certainty that she had at last been retrieved from the shadows and set down once more upon the bright lip of her life" (21). But is this sense of closure because she is assured that Samuel is still alive or because she can put him to rest? Selzer does not answer this question for us.

#### TOWARDS A BETTER SYSTEM

The example of organ donation portrayed in "Whither Thou Goest" does not entirely follow either the construct described by Mauss or the narrative of voluntary, altruistic, anonymous donation that is supposed to be practiced in the United States. From the perspective of Mauss's writing, in some sense Hannah did feel obligated to donate, due to the pressure she perceived from the doctor at the time of Samuel's death. After she contacts Henry, Henry felt the need to reciprocate, demonstrated by his eventually allowing Hannah to visit. The relationship that was created by Hannah and Henry was confrontational and truncated, rather than something that would strengthen societal bonds. In terms of the current practice of organ donation, the system was engaged to follow a voluntary, altruistic, anonymous path. However, following these standards led to a poor outcome for Hannah, as she was unable to find an outlet for her grief without going against the system. Again, the true voluntariness of the donation from the beginning is in question. However, the donation process was intended by those around Hannah to be both altruistic and anonymous, and it remained this way for several years. But, after three years of unrelieved grief, Hannah crossed both of those boundaries when she decided to locate and contact the Popes.

Instead of following one of the proscribed narratives of organ donation, Selzer has presented an example of how the organ donation process can go awry. Whether or not we believe that organ donation should follow the narrative of gift giving by Mauss or the standard set by the transplant

community in the United States, the intention of both practices is to provide benefit to both society and the donor families. The hope is that the act of organ donation will provide some small comfort to the donor families, but at minimum it should not intensify their grief. Through Hannah's experience, Selzer provides us with an example of how the system can fail donor families rather than support them. Even though she did eventually find closure, she had to go outside of the normal system in order to do so, committing fraud to find Henry's name and address and resorting to harassment to convince him to meet with her. Furthermore, this story provides an example of the conflict that might arise among donor families and recipients and their families who now find themselves connected through the organ donation process. Both parties initially enter the relationship anonymously, and likely neither party truly understood the implications of that relationship. One can easily imagine that Henry and Inez accepted the organ during a time of stress, focusing only on Henry's dire situation and not envisioning that, years later, the donor's widow would demand to enter their lives. Likewise, Hannah herself is surprised by her need to meet the recipient of Sam's heart so that she can attempt to find closure. Had Hannah not pursued the meeting so vigorously, she would likely still be grieving.

Ultimately, this story is about Hannah's journey to accepting her husband's death. It is unclear whether her grieving process might have been easier or shorter had she never agreed to donate his organs. But most families have positive experiences with the act of organ donation, and Hannah clearly did not. Donating Samuel's organs led to distress rather than closure, as she tried to understand what that meant for his death and for her as his widow. In presenting this story, Selzer challenges the transplant community to find a better way to envision organ donation, so that donor families do not regret the decision years later as Hannah did. Current practices of decoupling and using in-house coordinators have hopefully improved the consent process so that donor families can make as informed a decision as possible. However, the potential conflicts between how much of a relationship the donor families and recipients should have is not easily resolved. Sharp's and others' work shows that

individual and family responses can vary greatly, such that the experiences of one family may not parallel the experiences of another family.

## CHAPTER 4

### SHARING IN JOHN IRVING'S THE FOURTH HAND

In John Irving's The Fourth Hand, Patrick Wallingford is a photogenic, but otherwise mediocre television journalist who himself becomes a news item when a lion bites off his left hand while he is reporting a story at a circus in India (Irving). The incident is captured live on television and transmitted around the world, becoming what we think is the defining event of Patrick's life. After the traumatic amputation, Patrick resumes working as a journalist, and his string of casual relationships with women continues with no interruptions; he actually finds more success in both pursuits due to his newfound fame. Patrick's desire for a hand transplant is purely for aesthetics, a way to correct the disfigurement resulting from the loss of the hand and a way to counteract the pity others feel towards him. For Patrick, a hand transplant was a luxury rather than a necessity, and as the novel's narrator points out, "for what he did, wasn't one hand enough?" (5). But just as a journalist can change the narrative in a report by focusing on a different angle, Patrick wants to change the focus of his own story by replacing the traumatic amputation as the defining event of his life with the more redemptive story of being a hand transplant recipient. His transplant surgeon, Dr. Nicholas M. Zajac, treats hand transplantation as a step to building his reputation, searching for both recipients and donors through a website, [www.needahand.com](http://www.needahand.com) (44). Patrick's eventual donor, Otto Clausen, is brought to their attention after Otto and his wife, Doris, see the television coverage of the original accident and Dr. Zajac's search for a donor. Doris convinces Otto that if he were to die then his hand should go to Patrick. Despite Otto's young age and apparent health he subsequently dies of an accidental gunshot wound, thus providing the donor organ.

If the novel were to end here, it might be no more than two tragic stories, the loss of a hand and the loss of a life, united by one selfless gift of organ donation. The actual emphasis of Irving's novel is

how the transaction of a donor organ affects everyone involved: donor, recipient, and people within their social circles. In the acknowledgments to The Fourth Hand, Irving explains the inspiration for writing this novel:

Janet [Irving's wife] gave me the idea for *The Fourth Hand*. One night we were watching the news on television before we went to bed. A story about the nation's first hand transplant got our attention. There were only brief views of the surgical procedure, and hardly a word about how the patient—the recipient, as I thought of him—lost his hand in the first place. There was nothing about the donor. The new hand had to have come from someone who'd died recently; probably he'd had a family.

Janet asked the inspiring question: "What if the donor's widow demands visitation rights with the hand?" (316)

Thus, the character of Doris Clausen, with her demand for visitation rights, was born. But Irving does not limit his narrative to Doris's experience alone. He delves into the consequences of the donation for both Doris and Patrick. Unlike Richard Selzer's short story "Whither Thou Goest," which focused on the aftermath of organ donation for the widow, Hannah, Irving's novel imagines the implications of this transaction within the personalities of several distinct characters. Irving also strays from currently accepted practices surrounding organ donation, whereas Selzer painted a fairly conventional story of the process of organ donation. By presenting a system that is different from current practices, Irving envisions an alternative approach that may have advantages over the current system. I will also in this chapter consider how Mauss's understanding of gift giving can illumine what Irving's novel reveals about the complexity of organ donation.

#### VOLUNTARY, BUT NEITHER ANONYMOUS NOR ALTRUISTIC

Doris Clausen's decision to donate her husband's hand is unusual in many respects, and it strays from the current standard of a voluntary, altruistic, and anonymous donation. There is no question that the donation is voluntary. Doris has contemplated this donation far in advance of Otto's death, and cajoles Otto into agreeing. Otto even signs a letter that Doris composes and sends to Dr. Zajac describing their willingness to donate should an accident occur to one of them. In this sense, the letter

exemplifies the right enshrined in the UAGA to determine prior to death what should occur with one's body. What makes this situation unusual is that it mirrors the experience of living donors, rather than the families of deceased donors, due to the time she and Otto had to contemplate donation. Unlike its voluntariness, Doris's decision to donate Otto's hand to Patrick after Otto's accident does not conform to the current construct in the United States of organ donation as an anonymous, altruistic gift.

At first glance, the most obvious departure from current social norms is that it is not anonymous: Doris and Otto know who Patrick is due to his celebrity and have decided prior to Otto's death that his left hand will be bestowed upon Patrick. The practice of a donor family designating a specific recipient is termed "deceased directed donation," and according to OPTN at least 100 such transplants have occurred in the United States.<sup>16</sup> The practice is possible in relation to the provisions in the Uniform Anatomical Gift Act, based on the belief that a donor family would have an understandable desire to donate an organ and potentially save the life of someone with whom the family or donor had a preexisting relationship (Zink et al.). Also, based on legal precedent, a person has the legal right to designate what might happen to his or her body upon his or her death, and this would include designating potential recipients of organs (Sadler and Sadler).<sup>17</sup> However, this has led to some potential recipients using traditional media outlets and social media to publicize their story in the hopes of reaching families considering organ donation. This practice has been questioned by ethicists who believe it favors potential recipients with greater wealth and means, violating the concepts of justice and equity for those on the waitlist who do not have the opportunity to publicize their story (Cronin and Price). Some ethicists suggest that the practice should be limited to only designating family members as

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<sup>16</sup> <https://optn.transplant.hrsa.gov/news/optn-information-regarding-deceased-directed-donation/>, accessed November 12, 2017.

<sup>17</sup> One poignant example is that of Chester Szuber, a heart recipient. He was on the waitlist in 1984 when his youngest daughter, Patti, died from injuries sustained in a motor vehicle crash. He subsequently underwent successful transplantation with her heart, and has survived over 20 years. Patti's other organs were allocated to recipients off the wait list. (<http://www.freep.com/story/news/columnists/jim-schaefer/2016/07/16/chester-szuber-heart-transplant/87098726/>, accessed 11/11/17).



recipients, the practice is currently permitted both legally and administratively (Zink et al.). That celebrities have a clear advantage in this regard is obvious, as many fans feel a connection to celebrities that might influence their willingness to designate a celebrity as a recipient. This is the exact situation Irving has presented readers in the case of Doris donating Otto's hand to Patrick. Although deceased directed donation is not common, let alone to a celebrity, it is in line with current policies.

Irving creates a character to take the designated donation further. Doris delineates two conditions that she would like met before moving forward with the transplant. First, she accompanies the hand from Wisconsin to Boston and insists on meeting Patrick in person prior to the procedure. Unlike most donor families, she breaks through the theoretical wall of anonymity normally maintained in cases of deceased organ donation. Doris's second condition is even more unconventional than the desire to meet the intended recipient: she has requested visitation rights with the hand after the transplant. Because designated donation is so rare, and since it normally does involve a recipient with some sort of preexisting relationship to the donor family, there exists no specific guidance on protecting a recipient who happens to be a celebrity from unwanted intrusion into their personal life by an admirer. Readers can only guess that, should such a situation occur, the donor family and recipient would be expected to go through the existing process, in which letters are delivered via the OPO to both parties and meetings would occur only if both parties agreed. If anything, the OPO would have a greater interest in protecting a celebrity recipient from intrusion by the donor family due to the benefits a donor family might receive – fame or money – that goes beyond a psychological urge to identify the deceased donor living through the recipient. The potential for abuse is obvious. Although the fact that Doris's donation of Otto's hand is designated for Patrick would be permitted under current practices in the United States, her demands for visitation would not be so readily accepted.

Irving, as the narrator, uses Doris's requests to make readers question current norms pertaining to organ donation and anonymity. Due to the experimental nature of performing one of the earliest

hand transplants, Dr. Zajac has had to consult medical ethicists. This is despite the fact that he “didn’t trust medical ethicists . . . they were always meddling – doing their best to make surgery ‘more human’” (112). Dr. Zajac’s response to Doris’s request is surprise, referring to her “unheard-of-zeal” (110), although “the medical ethicists *loved* Mrs. Clausen’s request” (112). As readers, it is implied that we should agree with the ethicists; we assume that by their very nature as ethicists they are promoting the “correct” interpretation of this situation. Dr. Zajac’s impatience with the ethicists, illustrated by his scoffing at their humanity, is intended to cause readers to concur with the ethicists. Irving assigns the more conformist response with Dr. Zajac and the more unconventional response with the ethicists, thus subtly challenging the reader to take the unconventional view.

Irving’s maneuver concerning the ethicists also challenges readers to address the issue of altruism as it relates to organ donation. Even the chapter title in which these events take place, “The Strings Attached,” underscores the notion that Doris will not be satisfied by an altruistic donation. Organ donation as understood in the United States is meant to be a selfless act performed for the benefit of others with no expectation of recompense (Joralemon). The purported benefits of an altruistic donation should be psychological, in that the donor family’s satisfaction is based on knowing that recipients have benefitted and in being able to ascribe the moral good of the donation to attributes of the deceased (Markmann). In other words, an altruistic donation should have *no strings attached*. By donating Otto’s hand, Doris does not simply want to improve the life of a stranger for the stranger’s sake. She wants to ensure that she can continue to experience her late husband through visitation with his hand. Through Doris’s request, Irving is asking readers to question whether the purported psychological benefits, that simply finding joy in the benefit the donation brings to others, is enough of a benefit for donor families. Furthermore, by including the ethicists’ enthusiastic approval of Doris’s request within the narrative, Irving encourages readers to conclude that the psychological benefit is not sufficient.

## MAUSS'S CONSTRUCT

In the fictional universe Irving has created, the donation of Otto's hand has not wholly conformed to the narrative of voluntary, anonymous, altruistic organ donation. But neither does it correspond to Mauss's concept of gift giving. Recall that Mauss's construct includes the obligation to give, the obligation to receive, and the obligation to reciprocate. For the societies Mauss observed, gift giving did not necessarily require that there be a component of charity or even good will, as the gift giving relationship was at times used to reinforce hierarchies, demonstrate dominance over another person or group, or maintain peaceful ongoing relationships. What the three obligations are meant to emphasize is the underlying social relationships either created or maintained through the gift giving.

Any obligation Doris or Otto may have felt to donate the hand as a gift was not based on a preexisting relationship with Patrick, as most cases of both living donation and designated deceased donation are. One explanation might be that the Clausens are donating as part of a perceived obligation to help strengthen society as a whole. When trying to fit deceased organ donation into Mauss's construct, some have argued that the obligation to give is more akin to what one might experience when making a donation during times of war or natural disaster: the impulse to give is based on a feeling of solidarity with those affected even though one may not know the survivors personally (Joralemon). The fact that the Clausens see Patrick and his accident on television makes their story seem similar to this account of solidarity, like wanting to help victims of a natural disaster after viewing the devastation on television. The novel does not mention whether or not Doris agreed to donate any of Otto's other organs. In cases of deceased designated donation, usually the family does agree to donate other organs, besides the specific organ for the designated recipient, to strangers based on UNOS allocation procedures and waitlists. Given that Doris fails to donate Otto's other organs, an argument that the donation came from her perceived obligation to society as a whole seems less accurate.

Irving implies through this detail instead that Doris's motives were focused on this particular organ, the hand, being donated to this particular recipient, Patrick. The specific focus on Patrick renders the obligation to give much less strong as there was no preexisting relationship between Patrick and the Clausens.

The obligation to receive the gift and the obligation to reciprocate the gift fall to Patrick. It is actually Dr. Zajac who contacts Patrick, rather than the patient seeking the doctor. Zajac has seen Patrick's story on television, and in his pursuit of fame and career advancement sees in Patrick a path to both. Patrick may not feel an obligation to receive the hand, but he does want it. When Zajac offers him the opportunity to receive a new hand, Patrick replies "why wouldn't I want it?" (57). However, later in the same conversation he tells the doctor, "but no strings attached" (57), a phrase that foreshadows the demands that Doris will later make. Prior to meeting Doris, Patrick clearly has no intention of reciprocating the gift or in entering into any type of long term relationship with the donor's family. Patrick does not seem to be susceptible to the "tyranny of the gift" as described by Sharp. In this sense, Patrick approaches receiving the hand similarly to how he has approached most of the good fortune he had experienced in his life – with a passive expectation that he will continue to benefit from all the privileges of being an attractive alpha male and with little self-reflection about how this may or may not impact others. After telling Zajac that he wants no entanglements with a donor, Irving as narrator remarks "Patrick didn't give a second thought to the curiousness of his own comment" (57).

Patrick's expectation is that the transplant will occur through a charitable gift by an unknown family, with no relationship or reciprocity expected or offered. Patrick does not even entertain the notion that receiving a gift enters one into any type of mutually binding commitment with the giver. Doris, however, has an expectation of receiving some reciprocal benefit in return, and in fact requires that her requests be honored or else she might withhold consent to proceed. The stipulations that Doris makes do conform to Mauss's construct of gift giving by establishing their exchange as a true gifting

relationship, rather than anonymous, charitable gift giving that Patrick expects. Doris demands and is granted a relationship with Patrick that is initially defined by the gift of the hand from Doris to Patrick, the acceptance of the gift by Patrick, and the reciprocal gift to Doris of visitation rights with the hand—all of which has been approved by the ethicists. There is another way to interpret the exchange between Doris and Patrick that does not conform so easily to Mauss's paradigm: that of viewing the organ as a commodifiable object that can be exchanged for something of value.

#### THE DONATED HAND AS A COMMODITY

When Doris gives consent to donate Otto's hand to Patrick, her stated stipulations have already crossed the boundaries of anonymity and altruism practiced in cases of deceased organ donation in the United States. But her next request is a blatant strike against the concept of altruism in deceased organ donation. She has accurately assessed the monetary value of Otto's hand, both to Patrick as a potential new hand and to Dr. Zajac as an opportunity to promote his career. Doris commodifies this human hand. The hand is no longer a donation but a thing that can be bartered for something she wants.

What Doris truly wants is to have a baby, specifically Otto's baby, but unfortunately he was sterile. Her desire for children was present while Otto was alive, but after his untimely death it is understandable that this wish is more poignant, as a child would represent a living embodiment of her deceased husband. Doris believes becoming impregnated by Patrick, the man who will shortly bear Otto's hand, is an acceptable alternative. When she does meet Patrick, she tells him "If you respect me, I'll respect you" (116). She never overtly states that one thing will be traded for another, but there is no doubt that she is negotiating with Patrick – Otto's hand in exchange for Patrick's sperm. It is never explicitly stated, but strongly implied, that should Patrick not consent to all her requests, including the impregnation, she might not agree to donate the hand. To Doris, both Otto's hand and Patrick's semen are objects of trade.

The episode of sexual intercourse and the pregnancy that result are both problematic. In terms of the sexual encounter and the potential to become a father, Patrick's consent to proceed is ambiguous at best. Doris is moving ahead while the reality of what she is proposing is just dawning on him: "by the time Patrick leaned forward, to stop her from removing his undershorts, she'd already removed them" (117). The narrator acknowledges Patrick's discomfort, but he does acquiesce, although passively: "Wallingford protested, but when had he ever said no?" (117). As Irving has written the story, neither Patrick nor the narrator ever describe any regret on his part, even in regards to fathering a child despite no indication that he ever wished to be a father. The question of consent is not a topic to be taken lightly, but is a matter beyond the scope of this essay. Even though the ethicists have approved of Doris's request for visitation rights to the hand, they are unaware of her request that Patrick impregnate her, so we cannot assume that they would approve of this transaction. When Dr. Zajac reenters his office, he

could smell sex in the room. A medical ethicist might not have approved of this new development, but Zajac was a hand surgeon, and his surgical team was raring to go. (119-120)

Unlike the transparency of the request for visitation rights, no ethicist has been informed or approved of Doris's request to be impregnated. By portraying the act of intercourse as illicit and secretive, Irving allows the reader to contemplate the exchange without feeling that a reader must also endorse it.

Irving has created a setting in which Doris hopes to exchange Otto's donated hand for Patrick's semen. The number of patients waiting for an organ outnumbers the organs available, a fact which logically leads to the conclusion that the transplantable organs have monetary value. As a comparison, there exists a legal framework concerning the commodification substances that a body produces, such as blood or semen, but this does not extend to organs (Joralemon). One argument made against the sale of organs for transplantation is the discomfort many have with the commodification of organs because of what this implies for the idea of personhood. Christian authors have argued that what makes our body, and its constitutive parts, more than mere objects is that life itself is a gift from a

higher power, the embodiment of our souls. Donating our human organs to others respects and pays homage to the original gift of being alive, but selling organs would be an affront to the original gift and would ignore the inherent dignity of life (Hurley). A non-religious argument against commodification of organs is the idea of personhood, in which an individual has unique qualities and characteristics that would no longer be valid if a person's constitutive parts are reduced to interchangeable objects (Joralemon). Ethicists have attempted to imagine a system in which organs could ethically be sold or commodified (Zeiler and Malmqvist; Joralemon). Arguments in favor of selling organs for transplant typically emphasize a person's bodily autonomy to decide what happens to his or her own organs, a theory further supported by the concept of property rights (Hurley; Zeiler). A related argument against the sale of organs includes the potential for exploitation of individuals living in poverty (Zeiler; Zeiler and Malmqvist).<sup>18</sup>

Viewing a potential organ donation as a valuable commodity, as Doris does, is a theme present in many works of literature and film. Most works of fiction that present the selling of organs fall within the genres of suspense, crime fiction, and dystopic works, making Irving's approach through a comedic novel unusual (Frey).<sup>19</sup> What makes Doris's request unique, both within fictional works and academic discussions, is that she does not ask for monetary compensation but rather for payment with another bodily substance—Patrick's semen.

Irving presents Doris's proposal as a fictional alternative to altruistic organ donation. Rather than selling the hand, her goal is not a monetary transaction as much as an exchange of similar items.

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<sup>18</sup> A fictional example of potential exploitation is "Pretty Dirty Things" (2002) in which undocumented immigrants agree to removal of one of their kidneys in exchange for a forged passport, an illustration in which not only poverty but the fear of deportation compel these characters to undergo surgery which they might not otherwise consent to.

<sup>19</sup> As an example, one of the earlier fictional works to address the buying and selling of organs was Robin Cook's Coma. Coma portrays a young surgical resident, Susan Wheeler, who uncovers an elaborate scheme in which young, otherwise healthy patients are placed into induced comas, then undergo surgeries to remove their organs which are sold on the black market. Selling organs for transplantation on the black market after removing them from people who have been drugged against their will is the theme of a common urban legend and is also portrayed in several horror films, including "Turistas" (2006).

On some level, the exchange of the hand for semen seems more proportional than a sale involving money. Whether Patrick truly gave consent, thus supporting an argument for autonomy and property rights, is questionable. But, the proposal itself that the gift of the hand be reciprocated by the contribution of semen potentially falls within Mauss's paradigm. Doris's gift is Otto's hand, and Patrick reciprocates through impregnating Doris with his semen. Although problematic, Doris and Patrick do develop a mutual relationship. Mauss's requirements for gift exchange have seemingly been met.

#### THE HAND AS *SOBJECT*

There is symmetry in that what Doris has asked for in exchange for the hand is another *sobject*—Patrick's semen. Recall that according to Svenaeus' concept, *sobjects* are things that retain characteristics of both objects and subjects. Organs are *sobjects* because they can be treated as objects but they are also integral to the lived experience of a person, rendering them part of a person's subjective experience. Svenaeus further categorized *sobjects* as either *weak-identity-bearing-sobjects* or *strong-identity-bearing-sobjects* (Svenaeus). That Otto's hand is a *SIBS* seems obvious, because the hand is both a means for acting in the world and a method for experiencing the world around him, both contributing to his lived experience. The hand was also an externally visible part of his body, something by which he could be identified. Otto's hand was not only a *SIBS* for him, but also for Doris, because she had the lived experience of feeling his hand and interacting with it. Doris's desire to see and feel the hand after it is transplanted represents her continued wish to experience Otto, to feel comfort from the touch of his hand. Patrick's semen is a *SIBS* because the genetic potential for creating life endows the sperm with the power to affect his identity and experience through potential fatherhood.

In his novel, Irving portrays Doris's character going to an illogical extreme. As Irving has written this character, her belief that a pregnancy resulting from Patrick's semen represents Otto's baby strains credulity; Patrick himself questions this logic just prior to engaging in intercourse with her (117).



Believing that some metaphysical part of a deceased person lives on through the continued survival of his or her organs in another person is a common occurrence after transplantation (Sharp "Public Encounters as Subversive Acts"). Whether Doris truly views the baby as Otto's is never certain, and it is tempting to view her actions as resulting from extreme grief. But she publicly maintains this façade long after the baby's conception, announcing that she is pregnant with Otto's child during a televised press interview and even naming the baby Otto, Jr. In portraying her son as being Otto's genetic offspring, Doris transforms the belief that a donor lives on in a spiritual sense in a recipient to a literal belief that Otto continues live through Patrick. To Doris, Patrick's semen is literally Otto's semen, and she is therefore bearing Otto's child. The fact that Patrick clearly believes Otto Jr. is indeed his son implies that Irving as the author is not promoting Doris's fantastical view that the baby is genetically Otto's, only ascribing this belief to Doris's character.

However, despite Patrick initially questioning Doris's fantastical interpretation, Irving does incorporate mystical elements throughout the novel which would seem to support Doris's belief that perhaps a child fathered by Patrick is the same as a child fathered by Otto. Otto and Patrick both have experiences so similar that it would seem to represent a spiritual link between the two men. Prior to his death, Otto has a recurring dream in which he observes Doris giving birth while Patrick watches. Otto, having already consented to donating his hand in case of an accident, foresees the pregnancy that will result:

What was wrong with the dream was that the lion guy had two hands and was holding the newborn baby in both of them. Suddenly Otto's wife reached up and stroked the back of his left hand.

Then Otto saw himself. He was staring at his own body, looking for his hands. The left one was gone—his own left hand was gone! (93)

Patrick, for his part, experiences sensations that seem to relate to previous experiences Doris and Otto shared. As readers we have already learned of the Clausen's lakeside vacations, and more specifically their dalliances on a boat dock. When Patrick is having intercourse with Doris just before undergoing

the transplant, he puts his right hand on her back and “at that moment, he could have sworn that her hair was wet—wet and cold, as if she’d just been swimming” (118). Later, after another intimate encounter with Doris, Patrick has a dream in which he remembers the sensation of smelling pine needles and hearing “water lapping against the bow of a boat—or maybe slapping against a dock,” but “the dream had seemed not quite his” (137).

#### THE INALIENABILITY OF THE HAND

By portraying these seeming psychic links between Otto and Patrick, Irving implies that the connection between Otto and Patrick is more than what would be experienced had they only exchanged some inanimate object or possession. Until his death, Otto had experienced a loving relationship with Doris. Both diehard Packers fans, Doris has the flu on the evening of Super Bowl XXXII, and Otto offers to stay with her but she refuses. However “it touched her deeply: Otto loved her so much that he would give up seeing the Super Bowl at the sports bar” (91). They shared a robust physical relationship, which is emphasized by Irving when he reveals “there was something about her tone of voice that could give her husband a hard-on. It didn’t take long either” (95). Patrick has a similar reaction to Doris’s voice that her late husband did. At their first meeting, when Doris is essentially bartering Otto’s hand for becoming impregnated, Patrick initially seems unimpressed with her sexual prowess. However:

Then he heard her voice; something had changed in it, and not just the volume. To his surprise, he had an erection, not because Mrs. Clausen was half naked but because of her new tone of voice. (116)

When Doris and Patrick meet for the first time, he notices Doris’s love for Otto, saying “you loved him very much. I can see that” (115). Then, only hours later, after Otto’s hand is transplanted onto Patrick’s body, Patrick realizes that he loves Doris. Not only did Patrick receive a hand from Otto, but also Otto’s emotions towards Doris.

After the transplant Doris continues to identify psychologically with Patrick, although it is more correct to state that she identifies with the hand. Patrick not only allows Doris to visitation rights, but he is the one who travels from New York to Wisconsin to see Doris every weekend. They often lie in bed together so that Doris can feel the hand. On one occasion:

His left hand twitched but there was no ache now. Patrick lay still, waiting to see what his new hand would do next. He would remember later that the hand, entirely of its own accord, went under the hem of Doris Clausen's nightie—the unfeeling fingers moving up her thighs. At their touch, Mrs. Clausen's legs drew apart; her hips opened; her pubic hair brushed against the palm of Patrick's new left hand, as if lifted by an unfelt breeze. (135-6)

In this passage, Irving emphasizes that the hand is acting without input from Patrick, as if Otto still controls the hand. Certainly Doris responds to the hand as if it was Otto in bed with her, not Patrick. Doris responds intuitively, reaching for Patrick's genitals. But as soon as she feels his genitals she lets go, because once she realizes that it is Patrick and not Otto "the spell was broken" (136). Later, when Patrick has to have the hand amputated due to immunologic rejection, Doris then rejects Patrick as he confesses his love to Doris. This occurs not long after Otto Jr.'s birth, and Patrick is unsure whether it is the loss of the hand or the arrival of a competitor for Doris's affections that cause her to lose interest. To readers, however, Doris's romantic rejection of Patrick appears to be a recognition that the hand which she had come to see and experience as Otto is no longer alive. When the hand is no longer there, Doris no longer needs to see Patrick.

One way to interpret both the psychic connection between Otto and Patrick, as well as Doris's interactions with Patrick, is to consider whether the transplanted hand is an alienable or inalienable gift. Mauss himself believed that all gifts retain some essence of the giver, and are thus inalienable. When both Malinowski and Mauss describe the Melanesian Kula ring, they recount the idea of *mana* or *hau* (Eriksen and Nielsen). Mauss describes the *mana* as a gift's "magical, religious, and spiritual force," a force that is present due to the object's history with its former owner and which is retained no matter how many future owners it may have. The *mana* is attached to the giver and the gift, which means that

“to make a gift of something to someone is to make a present of some part of oneself.” In addition, Mauss describes similar phenomena in Chinese civilization, that “acknowledges the indissoluble link that binds everything to its original owner” (Mauss). The way in which donor families identify psychologically with recipients illustrates their belief that a donated organ continues to bear the identity of the donor, as if the organ carries the *mana* of the donor to the recipient. Svenaeus’s concept of organs as *subjects*, and in particular *SIBS*, supports this interpretation. *SIBS* by definition bear the identity of the person who is the donor, and this identity is then transferred to the recipient.

Doris identifies the hand as Otto’s because it still looks and feels like Otto’s hand. Even though the hand is attached to Patrick’s body, she reminds him, “It’s not really your hand” (138). There is no question that the hand itself represents a *subject*, a body part so intimately tied to the identity of both Otto and Patrick that its utilization by both men leads to Doris’s conflated beliefs about Otto Jr.’s paternity. Prior to his death the hand was clearly Otto’s, but, after it is transplanted onto Patrick, Doris cannot fully relinquish its connection to Otto. The fact that Doris continues to see the hand as an extension of her relationship with and experience of Otto demonstrates that she does not view the ownership of the hand as fully passing from Otto to Patrick. Furthermore, Patrick’s almost instantaneous falling in love with Doris, mirroring Otto’s previous love for her, symbolizes the spiritual aspect that was transplanted alongside the physical hand. The love both men have for Doris is the *mana* that has transferred from Otto to Patrick. The inability to fully abandon ownership and its persistent *mana* render the hand inalienable, especially to Doris.

#### THE SHARING FRAMEWORK

After Otto’s death, Otto himself can no longer use the hand, but both Doris and Patrick continue to benefit from it. In effect, Doris and Patrick share the hand after Otto’s death. Patrick benefits from the hand not only as a replacement for his lost extremity, but also by being introduced to Doris and

developing a relationship with her. Doris benefits by being able to continue a relationship with Patrick, even though she relates to the hand as an extension of Otto. After Patrick's body rejects the hand and it is amputated, Doris then rejects Patrick. But despite the loss of the hand, they continue to develop a relationship, and the final chapters describe Patrick courting Doris, his proposal to her, and her eventual acceptance. Their relationship continues to develop and deepen, even without the hand present.

Discussions of organ donation within ethical and medical literature tend to focus on either the gift-giving paradigm, with its emphasis on altruism, or the property rights model, with its potential for either monetary gain or selling of organs. But trying to assign organ donation to a category of either giving or selling is problematic. Zeiler and Malmqvist discuss the false dichotomy that these concepts represent, emphasizing that motivations of donors are not always purely altruistic or purely monetary in nature, and thus overlap should be expected and even encouraged (Zeiler and Malmqvist). The Nuffield Council on Bioethics, an independent body that attempts to address various ethical debates in medicine, has approached the seeming dichotomy between giving and selling organs through the metaphor of a ladder. They envision a ladder with six different rungs to represent ways in which society might induce a person or family to donate organs of a deceased loved one, especially considering the worldwide organ shortage. Progressing through the rungs, they go from "altruist-focused" in the first four rungs to "non-altruist focused" for rungs five and six (Strathern and Wright). The first rung represents the most purely altruistic scenario, in which society would relay information about the need and potential good of organ donation to families in the hopes that families would consent to organ donation with no expectation of recompense. By the fifth rung there is allowance for financial incentives, so that the donor family does not have to bear costs associated with donation, and the sixth rung allows for financial rewards that improve the financial prospects of the donor family. What this array of alternatives emphasizes is that a donor's or donor family's motivations may never be purely altruistic nor purely financial. Limiting the

academic discourse about organ donation to these two opposing alternatives grossly underestimates the complexity of the decision to donate organs.

There is an alternative to this artificial dichotomy: the paradigm of sharing. Within this framework, organ donation does not concentrate on an exchange of goods, regardless of whether that exchange is altruistic or monetized. Rather the focus is on the development of relationships among the donor, recipient, and society that occur when something of such value as a living organ is exchanged between individuals. The emphasis on the relational aspect of sharing mirrors the importance that Mauss placed on building and strengthening relationships through gift giving. The sharing framework encompasses aspects of both giving and selling by allowing for a more nuanced evaluation of individual situations (Malmqvist and Zeiler). For instance, sharing would allow for the possibility that, in select cases, some type of remuneration or repayment, either through money or other services, may be permissible as long the transaction does not result from undue coercion by either party. The sharing framework falls in line with Mauss's concept of gift giving in that it allows for reciprocation for the original gift, unlike the mainstream medical establishments idea of altruistic gifting. Just as Mauss's theory stresses the overall benefit to society at large when such reciprocal gift giving relationships are upheld, the sharing framework also emphasizes the fact that the exchange involves a community rather than two individuals. Thus, through sharing, recipients are free to express their gratitude and are allowed to forge connections with the donors or donor families. Through these new relationships, the complex emotions experienced by donor families and recipients can be acknowledged and explored, rather than concealed.

Sharp contends that medical professionals have often viewed organ donation in a very different light than do the donors, donor families, and recipients (Sharp "Sharing Amidst Scarcity: The Commons as Innovative Transgression in Xeno- and Allotransplant Science"). As described earlier, the medical establishment insists on a convoluted system in which anonymity is maintained between the recipient

and the donor family, presumably as a protective mechanism to allow the recipient to heal without any added psychological stress that interacting with a donor or donor family might entail. However, recipients and donor families often progress beyond the initial stages of anonymous letters, gradually communicating and meeting without the veil of anonymity, and eventually developing bonds that mirror familial relationships. Sharp argues that, through the forging of these bonds, laypeople intuitively understand a truth that the medical professionals do not:

I assert that whereas professionals promote donations as permanent acts of loss and renewal, lay parties readily understand the same processes not merely as the giving away, but as the *sharing* of a donor's body parts *and* vitality. As a result, the process of sharing facilitates a merging of selves. (Sharp "Sharing Amidst Scarcity: The Commons as Innovative Transgression in Xeno- and Allotransplant Science")

Donors and recipients accept that organ donation is an act of sharing rather than the donation of a gift and that the organ itself represents a "special sort of living thing, or a vital part of something" that helps to engender new communities. In this sense, recipients and donor families instinctively accept transplanted organs as *SIBS* and these organs becomes the foundation for the new relationships that develop. Sharp further explains that the feeling of indebtedness recipients often have towards either a donor or donor's kin naturally leads to sharing their lives in other ways, such as participating in each other's life milestones like birthdays and weddings.<sup>20</sup>

## SHARING THE HAND

Irving presents the relationship between Doris and Patrick as a sharing relationship, which includes both reciprocity between the two and the development of a meaningful relationship. Doris's initial desire to donate Otto's hand began as a charitable impulse, even before Otto died, but there was

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<sup>20</sup> Popular media provides several examples of this, such as a wedding in which a heart recipient enthusiastically participates in the nuptials of the mother who donated her son's organs. In this example, the bride is even seen with a stethoscope listening to the recipient's heartbeat. This exemplifies the type of strong bond that has developed between people who otherwise would have been strangers (<http://nbc4i.com/2017/07/12/heart-recipient-becomes-surprise-groomsman-at-wedding-of-donor-mother>, accessed 7/12/2017).

never anonymity, and the exchange of the hand for fathering her child is clearly an exchange rather than a purely altruistic donation. Being able to dispense with anonymity and allowing for reciprocity after the donation are both allowed and even encouraged in a sharing paradigm, but would not necessarily be permitted in our traditional organ donation model. The relationship between Doris and Patrick develops and deepens over time, eventually leading to one of the most entrenched types of relationships that two people can share: marriage and co-parenting. Irving further emphasizes the sharing relationship by depicting an almost literal “merging of selves” between the two men, as both Otto and Patrick perform similar roles in Doris’s life. They both take on the role of her husband and, although Otto is not technically a genetic parent of Otto Jr., in Doris’s mind both men can claim some degree of paternity of her son. Irving’s depiction of Otto’s and Patrick’s shared dreams underscores this merging by portraying a spiritual connection between the two men’s psyches in addition to the physical sharing of the hand. Patrick’s and Otto’s sharing of spousal and parental roles is a symbolic representation of their embodied experience of sharing the donated hand.

Inherent in the idea of a sharing relationship is that the involved parties are enriched by the new relationships and experiences they find through these newly created bonds. Both Doris and Patrick have benefitted enormously from their ongoing relationship. If we imagine a more realistic version of this story, based on what would be considered standard practices for organ donation in the United States, Doris might have been able to direct the donation of Otto’s hand to Patrick, but it is unlikely that she would have been allowed to meet Patrick prior to the transplantation. Without their meeting, Doris would have been a childless widow, and Patrick would never have fallen in love with Doris. Based on what readers see of Doris, we can imagine that she might have met someone else in Wisconsin, likely remarrying and perhaps having children. Patrick, in all probability, would continue to have a string of lovers and most likely would not “settle down” with marriage and children. But this is not the story that Irving has written. Instead Irving allows readers to vicariously witness and experience the benefits of a



sharing relationship in regards to organ transplantation. The sharing framework, with its basis in reciprocity, is what allows Doris to give birth to Otto Jr., even though we as readers know Otto is not the father, and to move forward with her second marriage to Patrick. More impressively, through falling in love with Doris, Patrick may have experienced more personal growth and deepening personal connections that he might never have had otherwise.

Through the fictional universe he has created, Irving asks readers the same question Janet, his wife, asked him after seeing the story on the news: "What if the donor's widow demands visitation rights with the hand?" (316). In the current environment, the answer would entail writing an anonymous letter months after the transplant and hoping the recipient agrees to a meeting. But Irving creates a setting in which the ethicists do not reproach Doris, but rather agree with her wholeheartedly. Irving shows readers an example of what organ donation would look like if we as a society allowed for organ donors and recipients fully to participate in sharing relationships, rather than expecting these people to maintain an artificial distance. As several authors have argued, many families refuse to accept the anonymous, purely altruistic model that the medical establishment has attempted to impose on them, instead moving towards the type of relationships exemplified by Doris's and Patrick's deepening bond (Sharp "Sharing Amidst Scarcity: The Commons as Innovative Transgression in Xeno- and Allotransplant Science"; Sharp "Memory Work: Public and Private Representations of Suffering, Loss, and Redemption"; Fox and Swazey "Organ Transplantation as Gift Exchange"; Joralemon). In the end, Irving is asking readers to side with the ethicists, who tell Dr. Zajac that they love Doris's request for visitation rights (112), and fully to embrace the sharing relationship model.

## AFTERWORD

The difference between interpreting organ donation as a Maussian gift exchange or a charitable gift comes down to the relationship of the donor and recipient. A Maussian gift exchange focuses on the relationship, while a charitable gift assumes that the gift is given anonymously with no expectation of reciprocation. Without a relationship between the donor and recipient, the organ donation is charitable; with a relationship the organ donation recalls aspects of Mauss' paradigm. As I contemplate the experience of my patients and their donors, however, I believe that whether the donation is Maussian or charitable is not the issue of greatest importance. The tensions that arise between donor family and recipient are almost always due to incongruence concerning their desires to form and maintain a relationship.

Organ transplantation is correctly regarded as one of the successes of modern medicine. But in the case of deceased organ donation it is a success story that is made possible due to another patient's misfortune. The recipient's chance at a healthier life is only possible because the donor's family was in a situation in which modern medicine could not produce a life-saving miracle. It is human nature to want to celebrate the positive aspect of transplantation, but the grief experienced by the donor family should not be forgotten or dismissed. Grief is a universal human experience, but each individual and family experiences it differently. As the work of the many sociologists and anthropologists referenced in this project has demonstrated, many donor families welcome the chance to have a relationship with the recipient, providing a sense of comfort and closure. But to assume that a donor family should want or feel obligated to participate in a relationship with the recipient would be to deny the members of that family the personal experience of their grief. Expecting or forcing an interaction with the recipient would be an intrusion into that grieving process.

In “Whither Thou Goest” it is the recipient who wants to maintain anonymity, rather than the donor family. Selzer’s story is from Hannah’s perspective, such that we get very little information about Henry’s experience. But just as the grief of losing a loved one is a particularly individual experience, so too is the experience of illness, especially an illness that forces one to contemplate one’s mortality in such a profound way. It is easy to ascribe selfishness to a recipient who would refuse to honor a donor family’s request to meet. But, as with a donor family, to force a relationship would deny that recipient the ability to process their experience in their own way.

As the sociological and anthropological literature demonstrates, the inability to communicate or meet with the other party can cause distress for either the donor family or the recipient. The donor family may want to feel the connection to their lost loved one, while the recipient may want to express gratitude for the gift received. Because most of this literature focuses on surveys or first-person interviews, there are inevitably voices that are missing from the conversation, since it is very likely that not every person queried agreed to speak to researchers or took the time to respond to a survey. Due to ongoing medical care after transplantation, recipients are more readily identifiable and available for these types of studies. I suspect that the donor families that decline to participate in surveys and interviews are likely the same donor families that decline to communicate with their recipient families. These voices may always be absent from the conversation, but that does not mean that their experiences and preferences are unimportant.

The Fourth Hand presents the possibility of a sharing model rather than giving a gift to describe organ transplantation. The story Irving creates shows both Doris and Patrick benefitting from the exchange in numerous ways. However, even this model will not succeed if either the donor or the recipient wish to remain anonymous while the other wishes to have a relationship. Like most human relationships, although multiple parties are involved, each individual has effective veto power if he or she chooses not to engage with the other person. Recently, this fact became clear to me.

There are many public events surrounding organ transplantation, often meant as fundraisers for a particular transplant program or OPO. These events also serve as ways that families of both donors and recipients can publicly celebrate how organ transplantation has transformed their lives. Every year I run in several road races, called a “Donor Dash,” that benefit my local OPO, the Gift of Life Donor Program in Philadelphia. The Donor Dash is by no means a solemn ceremony, but rather a celebration, complete with balloons, dance music, and faux-fur dressed mascots. Families of both donors and recipients can form teams and they carry signs designating their roles, either recipient team, living donor team, or donor family team, the latter specifically for the families of deceased donors. The teams come up with names, and often wear matching T-shirts with slogans and mottos. Teams register with the OPO prior to the race, and the OPO provides webpages for teams that serve as fundraising portals. In my observations, the living donor teams always seem the happiest, and the largest. They are able to celebrate not only the improved health of the recipient but also the courage and selflessness of the living donor. Team names and T-shirts will refer to the donor as a “star” or “superhero.” One T-shirt I saw summed it up with “Team B—, Starring J—’s liver” and the date of the transplant. Similarly, the recipient teams representing patients who received an organ from deceased donors use words like “miracle” and, of course, “gift.” The donor family teams smile and take pictures just like the recipient teams, but they always seem a little more subdued. Their T-shirts often have a picture of their loved one and the date of his or her passing, and the word “angel” usually features prominently in both the team name and T-shirt. I have never witnessed a donor family team with the recipient team of someone who had received that donor’s organs, but I suspect most of these families who take the time and effort to honor their loved one in public would welcome the chance to connect with the recipients, if they have not done so already.

This past September I ran in the 4<sup>th</sup> Annual Delaware Donor Dash 5K, this year conveniently held on the grounds of the hospital in which I practice since I was on call that day. As usual, I never join a specific team, so as not to play favorites amongst my patients. Instead I use the time to catch up with patients I have transplanted and their families; this usually involves some hugging. This year as I wandered around making small talk, one team in particular held my attention. The team name on the sign was “Team BUD,” a name that would usually mean the recipient’s name is Bud. But the T-shirt they shared further explained that they were “Dashing for B—’s Unknown Donor.” The recipient had received a heart, but the donor family had declined any contact. Those five words on a T-shirt instantly crystallized for me all the complexities of the gift giving relationship as it relates to organ donation. Here was a recipient who wanted to offer thanks, to open a dialogue with the family that had given him so much. But somewhere there was also a donor family who wanted to remain anonymous, a family that for whatever reason was not inclined to enter into a relationship with the recipient, who did not expect or even want reciprocity. That the recipient still wanted to find a way to honor that donor and donor family speaks to the obligation to reciprocate that Mauss described and the “tyranny of the gift” espoused by Fox and Swazey.

Moving forward, how can the transplant community honor the differing wishes of donor and recipient? In order to respect the wishes of donor families like BUD’s family, the current system offers the best hope of respecting and maintaining that anonymity. But the transplant community should continue to recognize and support those donors and recipients who want to connect. Because no family expects to become a donor family, little can be done to prepare them for this situation. But better support and communication after the donation might prevent an experience akin to Hannah’s in “Whither Thou Goest.” For recipients, education about potential interactions with a donor family can and should occur prior to transplantation. Consideration of what a relationship with a donor family might entail is rarely discussed beyond letting potential recipients know that they can write letters to

the donor family after the transplant. Perhaps examples of what can occur could help potential recipients proactively determine how they want to proceed. Even exposure to literature such as the works discussed here may offer insight to these patients as they contemplate life after transplantation.

The works of literature presented here offer only two examples in what is an infinite number of possibilities. Both works speak to the emotional complexities that these relationships, or lack thereof, can engender. Ultimately, there is no foolproof method for relieving the tensions that might arise between donor families and recipients. The most we can do is to protect the interests of those donor families and recipients who wish to remain nameless, while supporting the efforts of those who wish for some relationship.

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