

4-15-2016

The Organ Donation and Transplantation Process: What Young Adults Know

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Abstract

Popular messaging and how people talk about organ donation focuses on why people should be donors rather than on the process itself. The purpose of this thesis is to gain an understanding of what young adults know about the organ donation and transplantation process, how they interpret donor registration campaigns, and the discussion and decision process they have gone through, as a way to gauge their knowledge and action with the details and expectations of the transplantation process. This thesis found that young adults in the Cleveland, Ohio and Chicago, Illinois areas understand organ donation as a way to give life, a gift. Predominantly using the gift metaphor de-emphasizes sharing donation wishes with next-of-kin and the donation process. Using a wider variety of metaphors, such as recycling, to relay messages about the transplant process may initially be uncomfortable, but promotes discussion and more fully promotes an understanding of the process.

Document Type

Thesis

Degree Name

Bachelor of Arts (BA)

Department or Program

Sociology and Anthropology

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Subject Categories

Anthropology | Sociology

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Thesis Title: The Organ Donation and Transplantation Process: What Young Adults Know

LAKE FOREST COLLEGE

Senior Thesis

The Organ Donation and Transplantation Process: What Young Adults Know

by

Megan Crocco

April 15, 2016

The report of the investigation undertaken as a
Senior Thesis, to carry two courses of credit in
the Department of Sociology and Anthropology.

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Krebs Provost and Dean of the Faculty

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Abstract

Popular messaging and how people talk about organ donation focuses on why people should be donors rather than on the process itself. The purpose of this thesis is to gain an understanding of what young adults know about the organ donation and transplantation process, how they interpret donor registration campaigns, and the discussion and decision process they have gone through, as a way to gauge their knowledge and action with the details and expectations of the transplantation process. This thesis found that young adults in the Cleveland, Ohio and Chicago, Illinois areas understand organ donation as a way to give life, a gift. Predominantly using the gift metaphor de-emphasizes sharing donation wishes with next-of-kin and the donation process. Using a wider variety of metaphors, such as recycling, to relay messages about the transplant process may initially be uncomfortable, but promotes discussion and more fully promotes an understanding of the process.

To grandpa - I love you.

Acknowledgments

I would like to thank Holly Swyers for the endless knowledge, guidance, and opportunity to grow over the last three years. Thank you for always making sure I was sufficiently tasked and supported.

I would also like to thank Ryan Cook and Glenn Adelson for their contributions and encouragement as readers on my committee.

Thank you to my loving family for always supporting me in every possible way.

Thank my amazing friends, who inspire me every day.

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Introduction

In 1954, the first successful human organ transplant was completed. Since then, organ transplantation has become an industry that includes the Organ Procurement and Transplantation Network (OPTN), which is organized and maintained by the United Network for Organ Sharing (UNOS), local Organ Procurement Organizations (OPOs), hospitals, and people voluntarily registering to be organ donors, all of which work together to keep the system functioning. While the functioning of the organ transplant system is still a major undertaking, the idea of being able to get a life-saving organ has become common knowledge. Broadly comprehended as just and efficient in its functioning, the organ transplant system has led to a lack of asking questions that are more specific.

How does the organ transplant system work in the United States? Where does it fit? How did it develop? Why is organ transplantation commonly talked about as organ donation? How does organ transplantation reflect the commodification of body parts? Narrowing these questions as part of a larger system, how do people, specifically young adults, think about and understand organ donation and transplantation in the United States?

Start of the Organ System and Organ Shortage

An explanation of the basis of the organ system was necessary before answering my questions about organ transplants. Performed in 1869 the first skin transplant paved the way for the future of tissue transplant possibilities (U.S. Department of Health and Human Services 2016c). Vital organs did not see this medical advancement until 1954 when the first kidney transplant was successful. The first transplants consisted of living donors, but 1963 was the first time a brain dead individual served as a source of organ recovery (U.S. Department of Health and Human Services 2016c). Through the 1960s the

pioneering organ transplants consisted of with kidneys, hearts, lungs, pancreases, livers, and bone marrow. Once the United States medical community proved successful in transplanting vital organs, 1968 was the turning point in terms of establishing an organ system in the United States. 1968 was the year the Harvard Ad Hoc Committee established the testing criteria for defining brain death, in Boston the first organ procurement organization began functioning, and the Uniform Anatomical Gift Act was established (U.S. Department of Health and Human Services 2016c). With the gained possibility of potentially improving and prolonging an individual's life using the organs of another individual the organ shortage began.

Until the mid-1980s, the exploration of the possibilities of these new procedures led to the National Organ Transplant Act passing in 1983. The passage of this piece of legislation solidified the organ shortage in the United States. The Act most importantly established a fair way to distribute organs to people in need - the Organ Procurement and Transplantation Network (OPTN) and made it illegal to sell organs.

The medical knowledge to aid in the health of organs meant that anyone who had previously been suffering without a way of long-term treatment became a person who could receive a transplant if an organ match became available. Up until this point, there was never an organ shortage because there was no way for more than a few people to receive transplants and there was no national system to coordinate the exchange of an organ from one individual to another as a way of regular medical practice.

While the reasoning can be debated, the fact that over the last couple decades reports of vital organ failure have increased in both the United States and on a global scale remains (Abouna 2008: 34-38). There has been a need for organs, but not enough adequate donors to meet this need. Unfortunately, the number of people waiting on the transplant list has continued to grow. There have been several solutions proposed and

attempted to help combat the shortage of donated organs in the United States. Explained in Chapter 3, messaging has reached people in the forms of childhood curiosity, family beliefs, education and the high school and collegiate level, digital and print media, and getting a driver's license. Whether known or not, laws regarding organ transplants have influenced significant parts of the messages.

Organ Donation and Transplant Laws

The Omnibus Budget Reconciliation Act of 1986 made it so that hospitals had to offer families of deceased individuals the option to donate their organs. The Act was an attempt to help increase the number of deceased donors to help meet the number of living individuals that were in need of vital organs. In the 1990s and beginning of the 2000s, the central limitation of the organ donation system in the United States was that although it was the individual's personal decision to register as a donor, once the individual was declared dead and a viable organ donor candidate, their next-of-kin would have to give consent for the organ donation to take place. Until the mid-2000s individual states began changing their legislation, so the next-of-kin's consent after death was not necessary unless the deceased individual was not a registered organ. This change came because of suggested changes to improve the functioning of the system as well as to help registered donors have their wish for their body followed. For example, in Ohio, the consideration of multiple party interests were handled; but the next-of-kin's place in organ donation discussion technically used to be considered a property right, that the deceased's organs are considered their property to do with what they want. However, alterations to more accurately honor the deceased's wishes and the treatment of the process as a whole be more personal, rather than as the commodity market it had become (Stickney 2002: 74).

My Research Project

My research project was focused on how young adults handle the process of deciding to be an organ donor based on what they knew about the organ donation system and how they felt most comfortable hearing and talking about it. I wanted to know about how people learn, interpret, and develop a stance on organ donation. I needed to gather background information on commodification and the discussion in the context of organs and parts of a whole entity. I also need to develop a timeline of organ transplant development both medically and legally in the United States. These advancements resulted in the creation of a national organ system, a need for organs, and a new definition of death. I used the ideas of social theorists focused on how the view of the human body as fragments of a whole influenced the potential power of a body when regarded in terms of different parts and roles of organs on the life of an individual. Within the theoretical approach, the idea of body parts understood as a gift is a cornerstones of the portrayal of the organ transplant system. Also having a theoretical awareness of the distinction between the body and the self was an important part of conceptualizing the development of the organ transplant system. From here, I also needed to know concepts related to these theories, such as reciprocity, altruism, organ exchange, and how social theorists explain these concepts compared to how young adult participants think about the actions of an organ donor.

Learning about the history, theory, and ideas of organ donation studies provided an answer to my question about the development of the organ transportation system and ideas about why we have come to value our bodies for not only their ability as a whole, but that they have value as parts that can aid the whole. With the background to why theorists believe we value what we do and how the organ transplant system has established, I set out to discover how do young adults think about and conceptualize organ donation. As parts of a system that is constantly growing, how are young adults,

who are typically ideal organ donors, maneuvering the system? Knowing that organ transplantation is slightly different across the country, I considered the regional organization breakdown. My project's scope focuses specifically on how registration messaging plays a role in broader organ donation-related knowledge and decisions of a young adult in the two regions I had access to: Cleveland, Ohio, and Chicago, Illinois.

While my research specifically focused on the legal donation process of vital organs at the end of life including the heart, lungs, liver, kidneys, pancreas, and intestines in the United States, other transplantable parts of the body and the topic of black market organ selling and coercion were not the focus. It is important to mention the narrow scope of the organ transplantation discussions that took place, especially because of the common occurrence of organ selling and manipulation on the black market. Although the functioning of black market and its cultural influence are an important aspect of understanding organ transplants, it was necessary to limit participants in focusing on the legal channels by which they comprehend organ donation and transplantation in an attempt to improve the understanding and functioning of the national organ transplant system.

My question was broken down into three parts: what and how young adults knew about organ donation, what messages and metaphors they knew and understood, and how they approached the discussion and decision process. While national organizations guide the general functioning of specific regions and city-centers, I looked at more than one city to offer the potential to compare regional organization focus and messages. Young adults were a particularly appropriate population for an examination of organ donation beliefs as they were at a point in their lives with expectations about growing as autonomous decision-making entities. Exposure to messaging campaigns by organ procurement organizations as well as education, media, and discussions with other

people; culminated in making a donor decision recently. Each part of the interview addressed what people recall about information related to organ donation and how they felt about the concept, how familiar and comfortable they were with messages currently used to promote organ donor registration. Finally, I asked how participants approached their own decision of whether or not to register as an organ donor. The problem was that young adults were not necessarily thinking about how organ donation involves personal consideration about their decision as well as thought by family/next-of-kin. Donation decisions were important for individuals thinking about their donor status. It was also important for people to share their decision with their next-of-kin as a way of preparation for organ donation.

I also had to address areas of data collection. With two accessible regions for data collection, I examined them with the intention of identifying the similarities and differences in the way young adults interpreted and responded to the messages and discussion of their registration decision. Although messaging has been at the discretion of each individual organ procurement organization, the areas of Cleveland and Chicago are both major cities in the Midwestern United States. Compared to the different messaging styles of other regions of the country, these two areas had a similar broad messaging tactic. Both of these areas have undergone legal changes to the organ donor registration and transplant system that required more focus on the registration process. While the two cities shared some characteristics, the individual organ procurement organizations were in different organ regions, meaning their training and regional meetings were separate. The states themselves have different priorities and goals when it comes to donor registration, as well as different laws about when young adults first have the opportunity to register as an organ donor. While the two areas share some overarching similarities in their changes and messaging, there are specific regional and legal differences between the

two OPO regions. Analyzing the responses from these two different regions could help inform future messaging metaphors, ideas, and media for young adults in the Chicago and Cleveland areas based on what is working now. From my interviews, I ended up finding no substantial difference between the two regions. I concluded that young adults perceive organ donation as a positive process, but many are not receiving the donor registration messages that geared towards them. I found that young adults are not making informed decisions about organ donor registration.

As a society with a growing inability to meet the need of organ transplants, the registered donors in this country must also increase in order to have a chance to prolong peoples' lives. Overall, the goals of my research project were to identify how young adults conceptualized what it means to be an organ donor, what information they had about organ donation and how they got it, what registration messages and metaphors young adults knew and how they thought about them, and how they approached the discussion and decision making aspect of organ donor registration. Most important, the message that young adults receive needs to inspire engagement with the topic of organ donation in a way that improves their knowledge about the topic and desire to have discussions in order for informed decision making to occur. With a population that is more comfortable in their organ donor decision, inquiry about procurement can be more straightforward.

Current standards of organ donation knowledge have encompassed what transplants could be done, how brain death is defined, and debunking myths about the organ procurement process are falling short. Although campaigns were in place to increase registered donors, knowledge outside of the broad definition and an indication on a driver's license was not adequate for having people properly informed about the voluntary registration system in the U.S. The campaigns were also limited in how

different parts of a metaphor about organ donation actually related to a part of the system from a medical and legal perspective, and how discussions and support could lead to increased comprehension of the topic and preparation for dealing with a donation situation if it became necessary. Discussion could foster that knowledge, as well as education, and media content as sources to access information about organ donation. Ultimately expanding the metaphors used to comprehend organ donation could aid in catching the attention of young adults in the Chicago and Cleveland areas. Information was available from multiple sources, some of which are from the traditional national organizations and some are from regional campaigns, some are morally and ethically associated with discussion, and some are more scientifically robust in a classroom setting. Expanding on the explanation of organ donation on a national level could allow other effective ways of talking about donation to permeate into the areas of society that the current gift metaphor has already. Including recycling as a way to interpret organ donation could reach more people and parallel more aspects of the donation process. Using recycling as another way to portray organ donation can spark a discussion. Not only would this be a new way of talking about organ donation, but the fact that within only two cities there are a variety of reactions shows promise for incorporating ways of promoting organ donation that are not just the gift can get people's attention and encourage conversation.

Chapter 1: History of Human Body Use and Commodification

There have been multiple ways of considering the human body, such as a home for the soul or a way to live out the human experience. For the system of organ transplantation, a key development was being able to think of parts of the body as alienable, as commodities. Commodification of the human body was not the only way of thinking about organ transplants, but was a point that connected well with organ transplants referred to as gifts and donations, a focal point of my research project. How the human body has been used and conceptualized has shifted over time; however, the concept of social exchange being associated with the body has endured. Social exchange combined both a historical construct of organ use as well as a theoretical construct of how people thought about organ use. People who chose to donate organs became part of a larger historical and cultural process defining the perception and use of the human body. My goal was to learn how ideas associated with organ exchange developed over time, specifically how human bodies were valued and became commodified. Understanding the value given to the human body and its parts was crucial in comprehending how narratives around organ donation have developed. My research project questioned how young adults conceptualized the narrative of organ donation, which was crucial in determining if they viewed organs as commodities and how they participated in the organ donation system.

Historical and Theoretical Boundaries of the Body as a Whole and as Parts

Recognition of the human body as both a whole and as parts has shifted at different points of history in the United States. Regarding the human body as fragments has been associated with commodification. To explore how young adults in today's society thought about organ donation, I referenced the discussion by anthropologist Nancy Scheper-Hughes of organs as commodities. Scheper-Hughes broadly established a commodity as an entity given exchange value in a way it did not have before (2002: 2).

Scheper-Hughes discussed commodification of the body as a concept incorporating the body as an economic exchange, conceptualized in terms of— love, altruism, and kindness (2002: 2). The body being divisible into parts helped to establish organs as commodities (Scheper-Hughes 2002: 202). Human body commodification and fragmentation challenged the idea of wanting to maintain the personal boundaries and integrity of the body (Sharp 2000: 287). Even with this cultural inclination to maintain the self in terms of the body, scientific and medical advancements added to the discussion and view of the human body. Marcel Mauss, a sociologist, argued that commodification focused on the sociopolitical concerns influenced by sociality, power, and hierarchy (1967: 5). By this, Mauss emphasized how specifically the owner and the collective history of the entity influenced commodified entities in the social context. In the context of my project, the idea of commodities influenced by both the individual who made the decision to be an organ donor and the expectation of the transplant system were both at work. In terms of commodification of the human body, the social value and power placed on the physical self was important in understanding the use of the body. The economic value of the human body became increasingly prevalent in U.S. society. A 1978 issue of *Forbes* published the calculation that there were \$700 million in “spare parts” in the U.S. and at the time, with the expectation that the organ transplant industry would grow quickly (Solomon 1978: 52). In the U.S. in 1998, there were more than 1,000 biotechnology companies focused on the use of materials from the human body (Nelkin and Andrews 1998: 31). Calculation and commodification of the human body in economic terms and the social realm were connected.

Social theorists also presented other perspectives of human body commodification. Orlando Patterson, a historical and cultural sociologist, offered a view of the dehumanized body as objectification, as social death (1982: 1-15). Such an idea

relating the use of the body for its physical and biological capabilities existed in terms of slavery, human trafficking, and surrogacy, but also to the transfer of organs. The view of commodification of the human body as a dangerous force that depoliticized and denied sociality of the body would deny ownership of one's body (Turner 1994: 38). In context, this means that the social and monetary value that placed on the human body and its ability to be broken down into parts as a way of transferring them has devalued the body. One body part capable of supplementing another part had value that made how an organ's associated with either the donor or the recipient can create an issue with how the messaging of the organ donation process to appeal and be sensitive to all parties.

Medical and Scientific Commodification

Although the developed ideas about the use and commodification of the human have shifted over time, the utilization of the human body specifically in the scientific and medical realms progressed. Medical science made the internal functioning of the body an important part of its study, especially since the late 1980s when organ transplants became more standardized compared to the trials and first successes from the previous decades (Richardson 1987: 195-198). One component of medical use has been research with cadavers. In 2000, a report stated that a dead human body had approximately 150 reusable parts (Hedges and Gaines 2000). For example, there have been trends in the medical community exploiting the poor or disenfranchising them by using their bodies for research and to create and continue the commodification of the human body as a way to gain knowledge (Richardson 1987, 66-100). In terms of commodification on a scientific level, dissection has been important as a way to learn about the human body and was a practice that engaged with the literal fragmentation of the body. From dissection of the deceased, the practice of surgery on a living person was the next step in the process. Surgery offered the reality of a more permanent change to the body; it

opened up the possibility of alteration of the body in addition to observation (Hirschauer 1991: 279-319).

The medical use of the body has resided in conjunction with the how the categorization of the body. Incorporating the ideas about how people conceptualized their physical self as something in which the mind and body as intertwined or separated was necessary when discussing the use of bodies in medical practices. By the early 1990s, society was at the point of “regarding ourselves as both technological subject and object, transformable and literally creatable through biological engineering,” emphasizing the greater extent to which humans could objectify themselves with technological advancements that aid in the transformation of the body (Morgan 1991: 30). Knowledge and technology continued to drive the commodification of the human body.

Commodification of the human body has occurred subtly in U.S. culture and as a commercial thing. Aside from the treatment of the body as something with monetary value, the reference and marketing of the body as malleable has remained. For example, the malleable body contextualized in terms of plastic surgery allowed the viewing of the body in parts focused on individually. Overall, the progression, innovation, uses and limits for the human body in the time of biotechnology have become greater than before (Andrews and Nelkin 1998: 53). The value that placed on the ability to alter the human body has become a part of the U.S. culture, making it harder to identify those values. However, medical procedures are only one way in which the body can be viewed in parts, some of the time the body can be referred to as individual parts as a way to most directly address subjects and objects. The theoretical approach to commodification and fragmentation of the human body addressed in this paper was helpful as a way of thinking about the organ donation and transplantation process in the United States; however, there were other ways to discuss fragmentation and commodification. The

reference of the human body in language showed resistance to the idea of complete fragmentation. For example, I could say that I stubbed my toe; and so reference to the self would be as a whole even though I acted on a specific part of myself, my toe.

Sharp made that argument that the more commercialized and fragmented the human body became through medical practices, the more dehumanized the body became (2000: 298). In today's society, there has been an expression of an organ shortage. However, just as the medical processes of transplants developed, the social understanding that organs can be acquirable and moveable for the sake of human health developed. The idea of there not being enough organs has become part of our created knowledge.

Redefining Death - Brain Death

A significant medical practice directly connected to the commodification of the body has been the definition of brain death. The Harvard Ad Hoc Committee defined brain death in 1968 (U.S. Department of Health and Human Services 2016c). Donor cards, specifically identifying a person as a registered organ donor, became a legal document in the U.S in 1968 as well (U.S. Department of Health and Human Services 2016c). Standards made it possible for organ transplants to take place regularly and on a wide scale. The new concept of brain death in the 1960s stated death of a patient that was not reliant on the stopping of their heart. With brain death the heart was still functioning and the body was in a state that could be maintained but the individual has “a permanently nonfunctioning brain” (Journal of the American Medical Association 1968: 85). The first definition of brain death was developed specifically for the pronouncement of death with “accuracy and urgency because of an increased awareness amongst the masses for an early diagnosis of brain death and the requirements of organ retrieval for transplantation” (Goila and Pawar 2009: 7). Brain death has been an important part of the organ donation and transplantation process because of the heart still being in a state to

keep beating to maintain organ function until harvested for transplant. The definition and reasoning of brain death's establishment fed into the value placed on the human body's use for organs.

Cartesian Dualism

In order for the transplantation system to be successful, there needed to be agreement on the view of the body, or at least an awareness of different views. Cartesian mind-body dualism was the idea that the body and personhood are actually entities that are separate and distinguishable. This dualistic view of the self and the body was pivotal for the acceptance of organ transplants. The discussion of the distinction and separation of the mind and the body was not limited. Csordas drew differences between the personal and the social body (1994: 95). Csordas focused on the display of different aspects of the social self influencing the number of bodies a person had. Comparatively, Douglas viewed the body as “a source of symbols for other complex structures,” meaning that the parts of the body were all connected and served a purpose and yet they all had their own function (1984: 115). Douglas paralleled the physical and biological body as a symbol for the function of a social body. Douglas further addressed this concept as the self and the society (1996: 4). On the other hand, Lock and Scheper-Hughes defined three types of body: the individual, the social, and the split perspective of a political and social body (1987: 6-31). The focus of categorization of the individual body was on the experience of a person in daily life. The social body was associated with connections and interaction with society, culture, and nature. The political body was more concerned with the control of the social and political realms. With a greater knowledge of outlook on the body in different frames, we could address the question of how it could play out when dealing with organ transplantation.

Theory of Organs as a Gift

The way people have thought about and value the body influenced beliefs on its use. Looking at the work of Marcel Mauss provided a way of thinking how organ transplantation was conceptualized and referenced gift just like organ donor registration messages. *The Gift* argued how gifts are understood as social exchange, which is comparable to my study discussing how organs have been commodified (1954). Drafted in 1968, the Uniform Anatomical Gift Act was the piece of legislation that established the Uniform Donor Card, which became a “legal document of gift” across the U.S. as a way of identifying people over 18 who wished to donate their organs and establish how to rank priority for reception of donated organs (<http://www.organdonor.gov/legislation/timeline.html>). From the first steps in the scientific and medical success, the legislation revolving around organ transfer relied on organized bureaucratic structure. The United Network for Organ Sharing (UNOS), the governing body overseeing organ procurement and placement on a national level, has eleven regions to facilitate the most successful organ transplants (U.S. Department of Health and Human Services 2016a). The language of donation and gift giving, aided in regulation of the start of the organ transplantation system in the United States.

The gift metaphor encompassed the message that giving an organ to another person was comparable and regarded by thinking about giving a gift. Within this idea of the organ as a gift was the concept of giving someone something that could be beneficial to a person, whether needed or wanted. When talking about deceased organ donation, the choice to be a donor and give the gift of an organ is a decision that could benefit someone who is in need of a new organ. Referring to the need of another organ to replace a current one as a way to potentially and hopefully extend a person’s lifespan and improve their quality of life would be a possible parameter of a gift. The participants I interviewed talked about the idea of a gift today being associated with "help[ing] save people,"

"provid[ing] a second chance at life," and giving "hope" to people in need of an organ transplant (Participants 28, 1, and 7). These ideas encouraged thinking about how organ donation fits with the view of the donation as something that to give to another person.

The language used to describe the situation of organ donation was rooted in the idea of the gift. Before organ transplants, the use of the phrase “gift of life” had ties to blood donation and surrogate mothers (Sharp 2000: 303). The idea of applying the term gift to something human was actually a familiar and standard concept; for example, it being a gift that someone was healthy or referring to the birth of a child as gift. Initially the organ transplantation system in the U.S. was associated with generosity; however, as the population grew, an “organ shortage” has settled upon the U.S. (Ben-David 2005: 49). The organ shortage inspired moral and ethical discussions about payment for organs and how it would influence the current system (Ben-David 2005: 49). Adding the factor of payment would potentially reinforce this system to be one predominantly rooted in economic power, making it a more influential component than the current donation system. The monetary component of the organ transplant system led to a progression of the role of organ transplants in terms of reciprocity and altruism in organ donation.

Theory of Organ Donation in Terms of Altruism and Reciprocity

While the definition of a gift explained something given without the expectation of repayment, a societal expectation of reciprocity has established itself. Having gift and reciprocity associated with one another raised questions about how being an organ donor could be an altruistic act. The transplant process could connect people to one another but would leave a recipient with a question of how to reciprocate the gift of an organ appropriately. While an organ donation could be a gift, a way to make a gesture, it could also be an altruistic and selfless act. Medical anthropologist Orit Brawer Ben-David summarized how to balance ideas surrounding giving organs as “only superficially

independent and voluntary; although almost any object [could] be transferred from the ownership of one individual to another in an exchange, in effect, society determines the cultural level on which objects will be used in this process” (2005: 55). Ben-David proposed a way of understanding how although gift has a definition, there can be unwritten cultural guidelines that influenced scenarios involving gifts. Culture has determined that people view organ donation as an altruistic gift, allowing these two concepts to blend into the best outcome of helping other people after death. However, the organ donation has only recently become a possibility, and issues still arise. Lock raised the point of how the idea of giving organs to a stranger would be out of the ordinary, which might have made people hesitate to donate their organs (2002: 10). A loved one’s death could be a way to save or improve the life of others, and for some people it has been thought of that the donor has continued to live on in some way by part of them being in another person (Lock 2002: 130). While thinking of the donor as part of the recipient has occurred in the United States, cutting the body open in order for the transplant of organs can be unsettling for individuals.

Ultimately, a statement of altruism on paper was not the same as interpreting an act as altruistic. The gift of life could be an organ donation, and understood as a selfless act that would help another person and inhibit the altruist. Although the concept of altruism could be referred to in spirit, the label of altruism is more rigorous. An organ donor would give the gift of an organ. The recipient could benefit from a new organ, but the donor (in the case of my line of questioning would be dead) dies which broadly lines up with the definition of altruism. However, the donor may have received some benefit by having the label of an organ donor. Young adults I interviewed most commonly agreed with the idea of organ donation because it would happen at a point where their lives could not continue. This raised the question of organ donation being altruistic if the

donor has no better chance at living with or without their organs. Similarly, the disassociation of a gift from reciprocity became hazy when reciprocity has become a part of polite social etiquette. Associating gift with reciprocity generally has not been an issue, but when gifted of an organ, usually anonymously, the question of how to show proper thanks and repay the donor for their life would be complicated. Discussion of the gift of an organ in terms of its altruistic label and potential for reciprocity occurs further in Chapter 3 and 4.

Chapter 2 - From History to Contemporary Ideas

Commodification and fragmentation of the human body has occurred in the recent history of the United States. The discussions of organ transfer in terms of body commodification have taken into account the ideas and conceptualization of the body and how it has been used, specifically in terms of how the physical body has value and its parts could potentially be transferred. These ideas led into the discussion of how people have conceptualized these concepts today when it comes to how the human body was commodified, used in organ donation, and how this decision could be addressed. This included ideas about the taboo of death in U.S. society, the representation of organ donation in the media and by organ procurement organizations. The current understanding and opinions held by young adults provided insight to these concepts.

Individualism

The view of the decision process of organ donor beliefs and registration can be either individual or collective. Ben-David expanded on the social agreements of transplantation to encompass concepts related to the body and death (2005: 148). Specifically, organ exchange was a process that has resulted in ambivalence (Bauman 1992: 107). The fact that organ donation required decision-making about one's own body resulted in feeling free about approaching both beliefs and actions individually. Even though people make decisions about their bodies many times a day, this was a one-time decision that can have a lasting effect on the donor's body. Individualism was the goal and the expectation in the United States, but organ donation needed acknowledgment at both the personal and collective level in order to function.

Americans have chosen to participate in this social exchange, but to have organ exchange as a functioning system for the nation can benefit from, young adults (in the case of my project) should have felt as if they had similar beliefs and took similar actions

as other people. Although the individual ultimately made the decision, there was a cultural understanding of donation as a good act. Ultimately, the individual choice of organ donation was elevated to a public rather than private matter, and therefore the matter of death to gain a less private ranking as well. Although this concept and interviewee responses will be furthered analyzed in Chapter 4, the idea of the individual decision-making process as a common idea should have been acknowledged in conjunction with other ideas and trends of today.

Taboo of Death

While the taboo of death was not a new topic, it was important to note that there has been a taboo surrounding death in America today. Although there are different ways to focus on the lack of discussion of death in today's society, such as the medical and media personnel trying to avoid the subject even though they had the most influence on the discussion (Walter 1991: 293-310). Broadly speaking, hiding the discussion of death did not always happen, but the view grew to be an unclean process as the abilities of science and medicine have expanded. Organ transplants have now provided possible chances at the extension of an individual's life with another person's body. In addition to the medical advancements, end of life organ donation came in light of someone else's death as a way to offset or delay declining health. Ultimately, the attempt to delay death could be part of the reinforcement of the idea of death as a taboo subject. Talking about a scenario in which death occurred for someone in order to prevent death for another person was a much harder discussion to have than other methods of prolonging life that were more individually focused and reliant, such as medication. The hidden process of death helped to reinforce the idea of individualism, of not having the wider community know about the details and feelings about a person's own health and body.

There has been an unwillingness of individuals, especially young adults, to have serious discussions about their feelings and wishes about their bodies. Although this concept and the specific interview analysis for the donor discussion and decision-making process was more fully explored in Chapter 4, the discussion of the taboo of death should be acknowledged as a current idea that can be connected to the organ donation process.

What Do People Know About Organ Donation

Based on the literature outlining past and current ways of using the human body, specifically as life-aiding parts, this prompted a need to understand the organ system in the United States. While UNOS, United Network for Organ Sharing, was already introduced as the larger governing body of the Organ Procurement and Transplantation Network (OPTN), more detail to understand the role of Organ Procurement Organizations (OPOs) was necessary. Although there have been national guidelines set for how the organ transplant system works, OPOs have been responsible for a lot of the interaction with the transplantation of organs and messaging of ideas. The basis of the transplant system through organizational involvement then helped to shape the first part of my interview.

Organ-Concerned Organizations

The Organ Procurement Organizations have been responsible for communication about deceased individuals. OPOs also work with next-of-kin about donation options for a loved one. The two main responsibilities of OPOs were set as increasing the amount of registered donors, specifically within their region where the area will directly benefit, and coordination of the donation process when organs became available for transplant. OPOs have acted as the primary source of communication after death. As part of the mission to register donors each OPO has community involvement and has coordinated the advertisements according to how people get information in that area – such as

advertisements on the bus, on television, in school, or in conjunction with a religious activity.

Although the establishment of Organ Procurement Organizations was with the same general role across the country, not all 58 organizations have functioned in the same ways. As time progressed, so did the methods of Organ Procurement Organizations for dealing with the family who has lost a loved one while at the same time balancing the discussion of organ donation. In 2001, a study found vast differences in the consent practices OPOs used, 31% stated that they follow the wishes of the deceased and 31% followed the next-of-kin wishes (Wendler and Dickert 2001: 329). The study found that 13% stated organs were procured with either consenting party (deceased or next-of-kin) or if neither objects, and 3% of OPOs followed different practices from the ones previously listed (Wendler and Dickert 2001: 329). In addition to the practices of these OPOs, the study addressed policies of individual organizations based on what they found to be important components of the decision-making approach. In fact, 48% of the OPOs at the time had an official policy about following either the deceased's wishes or the family's. The most interesting finding in this study was the most influential factor in the OPOs decision about how to handle a case. The most important factor of organ procurement consent for 48% of the OPOs that responded were the wishes of the next-of-kin, compared to 21% that valued the state law first and 11% that made decisions based on the wished of the deceased wishes. Overall, the study found that a majority of the donation decision influence was given to the deceased's power of attorney (56%), while only 11% indicated that organ procurement would be based on a document indicating organs as a gift, such as a driver's license, living will, or donor card. Studies such as this indicated a need for the legal parameters about how to address procurement in a fair,

regimented, and compassionate way rather than leaving it so fully up to the discretion of each individual OPO.

Part One of the Interviews

Guided by the organization of the organ transplant system and previous research the knowledge and attitudes of organ donation and transplantation by adults in the United States, the questions asked in the first part of the interview formed. The first two questions about the interviewee's age and primary residence growing up were to ensure the interviewee met the requirements of the project in terms of being a young adult, 18-29 years old and have lived in the Cleveland or Chicago area for most of their lives. These two factors were important to maintain because this project set out with the intention of comparing the knowledge and opinions young adults had in these two distinct organ donor regions. By having divided the country into 11 different regions, it aided in facilitating transplantation and regional education. Cleveland was part of Region 10, which consisted of Ohio, Indiana, and Michigan. Chicago was part of Region 7, which consisted of Illinois, Minnesota, North Dakota, South Dakota, and Wisconsin. Noting that the interviewees came from two different regions was important, because differences in general and legal information, as well as familiarity with different messages may have indicated a difference in promotions in each area. Each region's transplant professionals had their own educational events (U.S. Department of Health and Human Services 2016a). The specific meetings, activities, and information were regionally specific and could have result in differences in the average young adult in each region. Conducting background research led to the following questions in the first part of the interview:

Criteria
<ol style="list-style-type: none"> 1. What year were you born? 2. Where did you grow up?
Prior knowledge
<ol style="list-style-type: none"> 3. What do you know about being an organ donor? 4. Do you agree or disagree with the idea of organ donation, and why? (This is not connected to whether or not you are a registered organ donor). 5. Do you remember when and how you first heard about organ donation? If so, can you please tell me about it? 6. Have there been other sources – people, resources, organizations, media, etc. - that have brought organ donation/ transplantation to your attention? Please elaborate on as many as you can and on the content of each message. 7. Given the messages and experiences about organ donation that you have been exposed to, can you please tell me how you believe they have influenced your knowledge and personal feelings about organ donation.
Donor
<ol style="list-style-type: none"> 8. Have you been asked to be an organ or tissue donor? If so, where and how old were you? 9. Are you currently a registered organ donor?

Asking these questions about each person’s knowledge of what is organ donation, how they feel about it, and what they remember learning as a way of getting at general ideas. This allowed for the second part of the interview to go into more specific messaging not frequently considered or analyzed by the individual.

Sample Overview

Throughout the course of this data collection process, 39 young adults between the ages of 18 and 29 voluntarily participated in all three parts of the designed interview. The sample of young adults interviewed from both Illinois and Ohio were found using convenience sampling for the first few individuals. From there, I used snowball sampling at the conclusion of the initial interviews to identify more young adults to interview. I asked the participants if they knew any other young adults they thought might be willing

to participate in the research project, and so on. I took notes during all of the interviews, and only one participant chose not to be recorded during the interview. There are several demographic factors not explicitly requested in data collection such as gender, level of education, or religious affiliation because they were not significant in previous studies of organ donation registration. Individually addressed and analyzed, each part of the interview follows in the next three chapters of this thesis.

	Registered	Not Registered	Intend to Register	Total
Illinois	10	5	5	20
Ohio	16	3	0	19
Total	26	8	5	39

The table above provided an overview of the organ donor status of the interview participants asked in the first part of the interview. Out of the 39 participants, 26 of them were currently registered organ donors and five intend to register in the future. The eight individuals who were not registered either did not intend to register or wanted to know more about organ donation before they would consider registration.

Year

The age parameters for interview participation were set so individuals between the ages of 18 and 29 could participate. This window of age to identify young adults came out of previous literature on how to define young adulthood as well as what age groups have been looked at when it comes to organ donor registration. For example, a study of young adult opinions in the UK included participants aged 18 to 30 (Coad et al. 2013). When it came to organ donation in the United States, moving the age range down to 29 made sense considering the most prominent donor registration method was in conjunction with getting a driver's license. An individual had to renew their driver's license when they are 21, and then every four years after that; meaning when the

individual is 25 and 29 people were already be required to update their license, and would be at a location that should prompt them about their organ donor status.

In my study, the oldest participant was 28 years old and the youngest participant was 19 years old. The participants of this study have a mean age of 21 years old. Having a sample with an average age of 21 was useful because participants were able to recall a more recent time when thinking about or talking about organ donation because many had recently renewed their driver's license.

Location

The location parameters for interview participation were set to incorporate individuals in the general Cleveland and Chicago areas. The first part of the interview was to get at knowledge and feelings of organ donation looking at two different areas that fall under the jurisdiction of Organ Procurement Organizations (OPOs) in the two cities. There were 58 Organ Procurement Organizations in the United States, each of which was responsible for working to increase the number of registered organ donors in that area and to help coordinate the donation process. The OPO that served the Cleveland and Northeastern Ohio area was LifeBanc; and four other OPOs designated to serve other areas of Ohio (U.S. Department of Health and Human Services 2016b). The Gift of Hope Organ and Tissue Donor Network is the OPO that served Northern and Central Illinois, including the city of Chicago and its suburbs, with two other OPOs designated to serve in the other areas of the state (U.S. Department of Health and Human Services 2016b). The importance of interviewing young adults in areas close to local OPOs could have an influence on the exposure to state messages and campaigns that are present in these specific areas.

In my study, 19 of the participants spent a majority of their life around the Cleveland area and the other 20 participants spent a majority of their life around the

Chicago area. Illinois had recently received national recognition for efforts over the last 10 years to increase the number of registered organ donors in the state. Having a sample with relatively equal representation of two different OPOs in different national regions allowed visibility and distinction of the different ways in running campaigns and programs.

After the questions related to meeting the age and regional criteria, the next set of questions related to prior knowledge about organ donation was asked. Asking these questions about each person's knowledge of defining organ donation, how they felt about it, and what they remember learning as a way of getting at general ideas. This allowed for an idea of what the individuals knew off the top of their heads before the second part of the interview with specific messaging to see if they considered or analyzed the concepts differently. Generally asking what an interviewee knew about organ donation was helpful in knowing the widely understood components and showed where there was a gap in important information. Of the 39 interviews conducted for my research, every interviewee at least generally knew what organ donation was, even if they first said "not much" or that they "basically don't know anything" (Participant 28 and 10). Interviewees generally described organ donation along the lines of "giving your organs to someone who needs them when you die" and something you can "indicate on your license" (Participant 20 and 25). This question was helpful in learning that only two of the interviewees mentioned brain death as their knowledge of organ donation (Participant 1 and 36), and even then no actual details of what brain death means were mentioned. This finding was interesting because previous studies found that lacking knowledge of what brain death was and how it was associated with organ donation was an important factor in deciding to be an organ donor (Shah et al. 2014: 291). Broadly, a couple individuals in my study mentioned that organ donations frequently resulted because "something

happen[ed] prematurely” (Participant 26). Along the train of thought medical knowledge provided as a response to the question, two individuals mentioned the importance of matching the donor and the recipient in relation to blood type (Participant 26 and 37). Another participant pointed out that the transplantation “doesn’t always work...[they use] tests and matching” to determine if people are a match and that even when this is the case the body could still reject the organ (Participant 11). In addition to the medical understanding of organ donation, two individuals highlighted the fact that the United States has operated as an “opt-in” system where people make an “optional” or “elective decision” to register (Participant 14 and 36). For the individuals who mentioned the legal process of organ donation and knew the choice they had showed parallels to the concept of recycling being an optional system used in the differing registration message. Fitting the similar thinking of electing to participate in a system, both individuals responded positively to the idea of recycling was a way of talking about this process.

The next question in the prior knowledge section asked the individual if they agreed or disagreed with the idea of organ donation. The question was aiming to identify any confusions participants had with the process or if there was some dominant component either in support or in opposition to the idea. Of the interviewees, all 39 stated that they agreed with the idea of organ donation, even though eight of these individuals were not currently registered organ donors and did not have any intention to register in the future. The general sentiment was along the same lines as what people knew about organ donation; being an organ donor was an opportunity to help another person and was as a good thing. Of the individuals who agreed but did not plan to be organ donors, the common theme was that the donation process was good but it is “not for me” or “not for my family” (Participant 5 and 37). Such dismissive comments indicated the discomfort of the participant knowing that removal of parts of their body would happen or that their

parents did not feel comfortable with the idea. For many of these individuals, religious beliefs also played a role in their decision. Interestingly, the fact that helping others was part of their religious view was an aspect of support for registration, while the idea of leaving this world differently than they came into it was an aspect of religion in opposition of personal organ donation. Some people expressed their agreement in terms of a continuation of life, saying, “my body has lived. I’ll die better knowing someone else needs it; they deserve to live,” which is in line with the prominent gift metaphor (Participant 13). Another individual agreed with donation by saying, “why be wasteful” because even having the chance to help others in need is worthwhile (Participant 8). Using the term wasteful to describe not taking the opportunity to register as an organ donor lead to questioning how the interviewee would react to one of the messages later in the interview that encouraged a person to “recycle yourself”. The idea of recycling yourself had negative associations for many interviewees; they viewed it as calling their bodies waste. The fact that some individuals reacted positively to the recycling message was important later on when one participant explained that not taking this opportunity is what would actually be wasteful, just like throwing something in the garbage that could be recycled.

The next two questions in part one of the interview asked about the instances in which interviewees had previously come across or learned about organ donation, and aimed to see the retention of organ donation information and how people were encountering the different messages. The responses to the prior knowledge questions made it clear that the role of education and media outlets were the driving force of young adults hearing about organ donation and transplantation outside of their family. Whether or not these were the only sources that people are actually encountering messages about organ donation, knowing that this was where people were remembering the concepts

from was important. Knowing where young adults are searching for, exposed to, and remembering information can have an influence on how and what they know based on what information is present in different mediums. When it came to the first encounter with organ donation, several of the interviewee's parents had explained what the general idea was, several interviewees learned about it in a health course, and a few interviewees learned about organ donation for the first time when they were getting their license. From there, many of the interviewees referenced media, specifically movies like *Seven Pounds* and television shows like *Grey's Anatomy*, as a way they heard about organ donation (Participant 22).

Many interviewees also mentioned that organ donation as a brief topic in other classes during high school and college, such as biology and ethics courses (Participants 11 and 1). The prevalence of classroom settings indicated that while the ideas of individualism, hesitancy around talking about death, and media have gradually worked their way into the value system in the United States; the role of education must also be taken into account. While there are programs in place to visit, talk, and promote organ donation education, it was not currently required but only encouraged in public school curriculums in Illinois and Ohio. The push to have the topic of organ donation taught in schools has occurred in both states and passed in Delaware and California.

Several interviewees remembered that they had seen some type of advertisement to register as an organ donor on a television commercial, but off the top of their head none of them could think of a phrase used, only that the sentiment was encouraging donor registration. Where young adults were remembering hearing about organ donation – in school and on television – should be important to keep in mind when promoting future messaging. The presence of articles about donation stories and technology related to transplants has gradually been becoming more frequent ("The advancement of organ

transplantation" 2016). People have developed ways of indicating organ donor wishes on social media platforms like Facebook, and online registration systems for most states were available to make the process quick and easy while also having the ability to find additional information right at an individual's fingertips (The Facebook Effect 2013).

Overall, the questions in the first part of the interview helped to see if findings were consistent with previous studies and to expand on the understanding of organ donation by young adults. The questions were able to ask people what they knew and what details they remembered before going into the second part of the interview where I used quotes of messages from specific state and national campaigns. Ordering the interview this way gets at what the young adults thought when asked broadly about the topic and details of their experiences without giving phrases and metaphors introduced in the second part of the interview.

Going back to some responses to questions about what people know about organ donation and if they agreed with it, the optional system and ideas about what can be viewed as waste start to bring to light ways in which people were able to talk about organ donation in ways that fit the recycling metaphor, before they heard it. The fact that those individuals went on to have no objections to the recycling organs message was promising in terms of the lines of thought carried over when in a context that used a metaphor with accompanying analogies that fit their previous, personal beliefs.

Chapter 3 – The Influence of Messages

When it came to organ donation and registering to be a donor in the United States, the young adults I interviewed created opinions based on their level of personal experience with the topic. To discover the dominant metaphor regarding organ donation, I first outlined the hierarchy of organ donation material and message content that was in use by national and various state organizations connected to the organ donation and transplantation system. I then reviewed and analyzed the second part of my interview questions to illuminate any prior exposure the interviewees may have had to these messages, as well as how they reacted to, understood, and agreed with the messages about organ donor registration.

First, I went through the hierarchical structure of the messaging system as a way to evaluate the similarities and differences of the messages I used in my interviews. The hierarchy assisted in identifying the trends within the messages that the participants had the opportunity to identify. In this part of the interview there were 13 different quotes about organ donation used from national and state organizations. Of these 13 quotes from prominent sections of websites and other media campaigns about organ donation, six came from national organizations and seven came from state campaigns or organizations. I considered the content of the messages to select the 13 pieces of information for interviewees' reactions. The messages varied in length and amount of information. Presented first were the national messages; they had the greatest variety in length and information, with phrases that fit the dominant metaphor of organ transplantation as a gift, details about the process, an emphasis on donation, and the intent to help others. The state messages follow the national messages, with four from Illinois and two from Ohio. The state messages were all short phrases or sentences that do not necessarily emphasize the gift metaphor, but all still fell under the umbrella since they incorporated the ideas of

giving and helping others. Related to local and state-specific campaigns, the phrases should have been more familiar and better understood by the people in that area. The final message the interviewees was about was a phrase from California using the metaphor of recycling instead of the gift.

Broadly, the theoretical framework that aided in the conceptualization of referencing organ transplants in the organ system in the U.S. was the gift. Use of the gift in legislation concerning organ transplants and widely in national messaging campaigns about organ donor registration was common. Although many phrases and concepts fell under the gift metaphor, including giving the gift of hope and donating the gift of life, it was important to note how the term donation is associated with the gift. Usually selected and given with individual detail and intent, a gift differs from a donation. While a donation would be a type of gift, it was a faceless gift; it had similar intentions but a lack of relation. Throughout much of the messaging and participant responses, the use of gift and donation were interchangeable, offering support to the idea of a donation as a type of gift with an emphasis on the lack of distinction shown when using the terms when talking about organ transplantation. It was important to note that this section of the interview directly followed part one questions about what people knew about donation and what types of messages and media they remembered. Having people respond about what they naturally associate with organ transplantation and donation before hearing specific phrases that could have been familiar was important.

In the development of this part of this second part of the interview, I thought that there might be differences in knowledge, exposure, and feelings about the messages on a national and state level by people from different states. For each of the 13 messages listed below, the interviewees responded to them in order and their comments were compared to other participants from their region and then the group as a whole.

Organ Donor Registration Messages

National – gift metaphor	
<p>“The deceased donation process begins with a decision. You decide you want to help save people with end-stage organ disease by donating your organs when you die. When your time comes, perhaps decades later, your organs may be used to save many lives. People most frequently become donors after a stroke, heart attack or severe head injury.”</p> <p>“Donate the gift of life.”</p> <p>“Organ, eye, and tissue donation and transplantation provide a second chance at life for thousands of people each year. You have the opportunity to be one of the individuals who make these miracles happen.”</p> <p>“By deciding to be a donor, you give the gift of hope ... hope for the thousands of individuals awaiting organ transplants and hope for the millions of individuals whose lives could be enhanced through tissue transplants.”</p> <p>“You have the power to donate life.”</p> <p>“The gift of a lifetime”</p>	
Illinois – components of gift metaphor	Ohio – components of gift metaphor
<p>“It takes just a minute for you to save a life”</p> <p>“Be a hero”</p> <p>“Life goes on”</p> <p>“Wave away the waiting”</p>	<p>“Say YES to life”</p> <p>“It costs nothing. It means everything”</p>
California – recycle metaphor	
<p>“Recycle yourself. Become an organ donor”</p>	

The 13 messages not only represented the different areas in which participants indicated if they were familiar, but also showed the metaphor usage in the messages. The top and most abundant section of messages promoted donor registration at the national level. With the national messages, the gift metaphor was explicitly stated in three of the six quotes.

National Message as a Guide

The national level of organ donor registration messages broadly referred to the process as people would refer to a gift. The development of deceased organ transplantation in the United States emerged initially as a “gift” from the donor to the recipient and was still predominant during this research. An organ as a gift could be thought as something given without the expectation of receiving anything in return. While on the surface the meaning of a gift was simplistic, factors such as who the gift is for, the occasion, content, use, preparation, presentation, cost, and a person’s interest in the gift are all important components that can be conceptualized in terms of giving a gift. This checklist could be applied when the gift was an organ for someone to potentially benefit from. The gift metaphor encompassed the idea that the donor is helping other people, and that they were acting altruistically once their own life cannot continue. Within this larger metaphor of gifting organs is the idea of a “donor” and that the gift of an organ is a “donation.” Directly addressed as a gift, the metaphor hints at other components that fall into the gift of life, such as viewing it as a second chance or miracle.

The national messages set the tone for the breadth of content in the state registration messages. Run and maintained nationally, organ procurement and distribution has by happened through the Organ procurement Transplant Network (OPTN) and the United Network for Organ Sharing. The Organ Procurement Organizations in each state enter donor information into the national base for the two controlling networks; but the OPOs handle almost every other aspect of their operation. While national legislation has always talked about organ donation as a gift, this is a sentiment most prominent at the national level, while the 11 geographic transplant regions are used more administratively, and the specific content and strategies of donor registration messages are left up to the discretion of the OPO in that area. These explain why the state messages target concepts within the gift metaphor. The development of a

new recycling metaphor in several states is not surprising because although there are some critical differences between the two metaphors that set them apart in function and expectation, these two ideas can still relate to one another.

State Message Variation

From the explicit naming of gifts and donations in the national messages, the individual states with messages discussed in the interviews were using variations of the gift metaphor. State organ donor registration language had the same overarching messaging of helping and saving others by allowing their body to be used after death, but each state used phrases and concepts meant to specifically appeal to the population in that area. Each state used a phrase that appealed to the broad idea of aiding to prolong peoples' lives, whether it is the life of the donor or the recipient ("Life goes on" and "Say YES to life"). The Illinois messages also targeted the labeling of the person registering as a hero. The phrases used in Illinois appealed specifically to time used on the donor's side ("It takes just a minute for you to save a life) and on the recipient's side (wave away the waiting). In comparison, one of the Ohio phrases was specifically appealing to a person's perception and value of cost with the message by saying "It costs nothing. It means everything". Overall, the messages used by Illinois and Ohio reverted to the idea of the gift. Because an individual cares about how the recipient of a gift feels and can use it, they thought about gifts in terms of cost and benefit.

The bottom category of the chart indicates the metaphor that is different from the first two rows of phrases. The last phrase was in use in California, outside of the range of the two compared regions. In contrast to the previous messages, the California organ donor registration message urged an individual to "recycle yourself." While the gift focused on helping an individual, the recycling metaphor implied doing something that

helps everyone, which this process reused an important resource for used by following specified guidelines when it comes to preparation and procedure.

The concepts behind the recycling metaphor comparison to the gift metaphor were in Chapter 1. Both metaphors were broadly concerned with the idea of helping people; however, the gift metaphor was more focused individual-level aid, while the recycling metaphor focused on working as part of a larger society to help everyone rather than just a few people. The content of a gift was critical in terms of preparation and personalization, which emphasizes the importance of properly matching organs to recipients. The aspect of recycling guidelines does the same thing as a metaphor for organ donation except on a national scale by setting specifics for defining brain death, organ testing, organ matching. However, the same implication of overall reach was different between the two metaphors; with the gift on a small, individual level, while recycling was setup and recognized on a larger scale. While the sentiment of care for the individual with the gift metaphor may have provoked more of an emotional response, recycling offered a metaphor that could be broken down to get at more of the literal concepts incorporated in organ transplantation, invoking altruism to consider when deciding to register as a donor.

After getting a baseline of participants' knowledge of organ donation in the first part of the interview, the second part of the interview began with the most wide spread messages, followed by more regionally focused messages, and ended with a phrase that used a different metaphor. The incorporation of a different metaphor can be used to see how individuals react to the familiar concept of recycling as a way of thinking about organ donation, which was typically associated with gift-giving in some capacity. While the reaction to phrases within the first 12 messages was important in terms of knowing what aspects of the gift metaphor are more widely accepted, the comparison of the two

metaphors could help to inform continued organ donation and transplantation metaphor use.

Interview Reactions

While I was interested in seeing how young adults from the two different regions had exposure to commonplace ideas about organ donation and how they interpret them, I was also interested in seeing how they would react to and discuss a different metaphor. As mentioned previously, the interviewees gave their opinion of donor registration messages that were coming from different state and national organizations. Understanding the broad setup of the organ transplantation system in the United States was important to recognizing how all of the messages related to one another and why specific language was present in each.

State-Specific Messages

“It takes just a minute for you to save a life” – (Life goes on 2016)

Used in Illinois, the phrase above referred to the gift of organ donation as something that will “save a life.” The focus on the interviewee commentary on this message was split between young adults liking the sentence for its “accurate [depiction] of the registration” with a focus on the ease of the process and those that felt this message downplays the importance of the decision and the time the live-saving actually takes (Participant 13). This disconnect stemmed from the differences in recognizing what the message was trying to get at. It seemed to be geared toward the quick registration process, but many of the young adults were critical about how saving a life was a “possibility, but not every registered donor ends up donating their organs at the end of their life” (Participant 18).

“Be a hero” – (Life goes on 2016)

Just like the previous message, there was no familiarity to the message by either group. Some of the interviewees were okay with referring to an organ donor as a hero because organ donors are “giving an organ that could save another person, which is pretty heroic” (Participant 16). This message, although a bit exaggerated, fits the gift metaphor. Even though many of the young adults acknowledged heroes, most of them did not believe that an organ donor was or should be a hero. People noticed how selfish it would be to want to be considered a hero “for just doing the right thing,” with the general sentiment being people saying “I don’t think I’m a hero by donating [my organs]. It is a service” (Participant 8).

“Life goes on” – (Life goes on 2016)

This was the most recognized message from the interview, aside from the general recognition of the explicit gift messages on the national level. Although most of the people who recognized this phrase are from the Chicago area, a couple interviewees who found the phrase familiar were from the Cleveland area. The recognition of this message is not surprising because of its connection to a large campaign platform in Illinois led by the Secretary of State, Jesse White. Unfortunately, even with an increased rate of recognition by young adults in the state, they were still unsure about what the phrase meant. Although some of the interviewees liked that this phrase, and some others, were ambivalent, most of the interviewees found that not knowing if the message was referring to the recipient’s life, the donor’s life, or both was “frustrating and unhelpful” in recognizing the meaning the message was conveying and who it was for (Participant 12).

“Wave away the waiting” – (Life goes on 2016)

Not recognized by the young adults, this message was the most confusing of the 13 phrases. Nearly half of the interviewees did not know what the message was referring to, and when I addressed the question afterwards many participants stated that the waiting

referring to the length of the transplant list for an organ transplant was not obvious. Once people knew what the message was referring to they thought it was “cute” but obviously very vague not only in the context of organ donation but also in terms of how the process would be achieved since there was no mention of donor registration in the phrase, just like many other state messages (Participant 29).

“Say YES to life” – (Donate life Ohio 2016)

Many interviewees recognized the message above, but only because it closely resembles how the country has been referring to the stance on abortion as either pro-life or pro-choice. The focal point of this message was for the continuation of the life of a person needing a vital organ rather than the life of a fetus. The interviewees did not like the slogan being similar to another campaign, saying it was “unhelpful to the donor registration cause” (Participant 3).

“It costs nothing. It means everything” – (Donate life Ohio 2016)

This message also received mixed feelings by interviewees. While many of the young adults did not pick up anything except that it is once again a very vague message that leaves you unclear about what “it” is in this situation. In addition to the ambiguity not being helpful in trying to remember having seen messages like these before, the idea of cost was also an important point many people brought up. Ohioans responded more critically to this message, as well as some others, but it was helpful in seeing that young adults from Ohio were more critical of wording, content, and clarity of a message. While some interviewees pointed out that it was nice that there would be no monetary cost to the donor or their family, others focused on the cost of life and how “the donor would have to die” in order to make this possible, which sounded like a substantial cost to many of them (Participant 12).

National Gift Messages

“Donate the gift of life.” – (Organ donor registry 2016)

The phrase above was one of the national messages directly referring to organ donation as a gift. Although the general sentiment of helping to continue life by being an organ donor was recognized, interviewees did not recall the specific language used in this message. The only difference between young adults from the two areas was that the interviewees from Ohio were focusing on the ambiguity of this particular message, specifically because several people thought the phrase reminded them of “abused animals and adoption” more than organ transplants organs went unmentioned in the message (Participant 16). Overall, the young adults identified this as a loaded message because of its short mention of such an important topic. The interviewees understood the fact that a short phrase such as this did not tell the whole story and used to get people to pay attention and remember the phrase. Interviewees found it was asking too much of readers, which may help to explain why some of them were able to associate ideas related to animal life more manageable to both think about and take action, compared to a decision about their body.

“The gift of a lifetime” – (The gift of a lifetime 2016)

The phrase above was the second national messages directly referring to organ donation as a gift. Once again, some people recognized the general sentiment of this being a way they could see referring to organ donation. With no notable difference between the comprehensions of the messages in the two regions, the most interesting responses to this message also stemmed from its vague and ambiguous language. While people were accepting of the attempt to use a broad phrase, many interviewees once again had different associations with the message than intended. People regularly talked about how this phrase was not only cheesy, but reminded them of tacky “commercials about the importance of buying your wife’s engagement ring” or “the advertisement for a

relaxing getaway on a cruise for your anniversary” (Participant 13 and 28). Most of the interviewees also noticed how similar these first two messages were to one another wording.

“You have the power to donate life” – (Donate life America 2016)

The phrase above was the last of the national messages to directly mention gift. Once again, the response to this message was similar by both regions; the interviewees split in their thinking the phrase was a fine way to talk about the donor registration process and thinking that it was too aggressive. While some people found that this message was good at emphasizing that this decision and its power is with each individual when the word “you” is used. Some interviewees found this “empowering and inspirational” in terms of the difference every person is capable of making (Participant 30). The other half felt that the association of this gesture of donating an organ to help someone being referred to as a position of power “did not seem right,” that the power of one person over another was a negative way to think of this process (Participant 28).

Following the previous three messages that explicitly referred to organ donation as a gift, the following three national messages still relate to organs as a gift, but more focused on providing details about the process.

“The deceased donation process begins with a decision. You decide you want to help save people with end-stage organ disease by donating your organs when you die. When your time comes, perhaps decades later, your organs may be used to save many lives. People most frequently become donors after a stroke, heart attack or severe head injury”. – (United Network for Organ Sharing 2015)

This message was very clear in emphasizing that before organ transplants happen the “process begins with a decision” and why someone might need an organ because of “end-stage organ disease.” This message mentioned that while this decision is important, there would probably be no need to act on it until “decades later” and then list situations

that commonly lead to people being eligible as a deceased donor. While most people were happy to have learned about how specific conditions result in deceased donation, just as many people misunderstood what the last sentence of this message meant, believing that having one of these issues leads to those individuals registering as donors. Another negative reaction that some of the interviewees mentioned was the focus on death more than any other message and that it made them feel “sad and uncomfortable” with talking about the details of organ donation so candidly (Participant 24). The Chicago interviewees emphasized the focus on the use of “you” and the personalization of the decision, while the Cleveland interviewees were more interested in where a message was visible because of its “language geared toward death” (Participant 12). Even though people know they will eventually die and that we are talking about deceased donation, death was not a topic interviewees wanted to have in the message.

“Organ, eye, and tissue donation and transplantation provide a second chance at life for thousands of people each year. You have the opportunity to be one of the individuals who make these miracles happen”. – (Organ donor registry 2016)

This national message was unique in its use of “second chance at life” to talk about organ donation. While a couple people recognized the sentiment of what this phrase means for organ recipients, interviewees were not very familiar with it. There were two meanings of “second chance at life” either for recipients to have the chance to prolong their life by getting an organ or for the donor to continue to live on in some way in another person. Noted by participants again, there was an emphasis that this opportunity was on “you.” One of the most controversial points was the use of the word “miracles” to describe the transplant process. Several interviewees pointed out that they were religious when they heard this message; they said that referring to life, as a miracle is “closely in line with [their] own beliefs” (Participant 22). On the other hand, some

people regardless of any mention of personal belief took offense too comparing human action to a godly and supernatural action, as if the science and teams of peopling working on a transplant is only possible because of a miracle.

“By deciding to be a donor, you give the gift of hope ... hope for the thousands of individuals awaiting organ transplants and hope for the millions of individuals whose lives could be enhanced through tissue transplants”. – (Organ donor registry 2016)

The final national message used “hope” as the gift that donors are giving to the recipients, not just an organ. The use and expanded meaning of hope to encompass their “spirit rather than just [a recipient’s] living body” was one of the most positive reactions to the messages (Participant 23). The new information in this message also sparked interest and learning about tissue transplants because this project is focusing specifically deceased vital-organ donation and did not focus on blood or tissue unless mentioned by an interviewee. This message made it clear that people are in need of organ and that once again, “you” have the power to do something about it.

Recycling Message

“Recycle yourself. Become an organ donor” – (Recycle yourself 2016)

The metaphor of recycling was as a point of comparison for the predominant use of the gift as the metaphor to describe the organ registration, donation, and transplantation process in the United States. While this campaign message was specifically from California, several other western states have been using this metaphor in recent years. None of the interviewees had ever heard organ donation and recycling compared to one another before. The response to this message ended up being the greatest split between opinions and interpretations of any of the messages interviewees talked about. Whether or not the interviewee ended up commenting positively or negatively to this phrase, they paused, looked uncomfortable, starting laughing, and many

would look at me with shock and disgust. The negative reactions to this metaphor usage focus on the lack of value given to humans, with several participants saying that this belittled humans into something equivalent of “trash” (Participant 5). Generally, people claimed recycling was not a way they wanted to think about themselves or their body. On the other hand, the interviewees with positive reactions to the recycling message could not articulate why exactly they found this message more helpful or appealing. One of young adults tried to explain that the recycling message “[was] a way of looking at it more scientifically” and that they liked the sound of recycling being a more worthy cause and reference to helping others than gifts were (Participant 2). Interviewees that liked the recycling message could see “clarity in the system” (Participant 13).

Conclusions

Overall, the only substantial difference between the interviews in Illinois and Ohio was that young adults in Illinois were somewhat more familiar with the messages and phrasing used specifically by organ donation and registration campaigns in Illinois than Ohioans were of the messages used in their home state. While young adults in both states understood the general concept of organ donation similarly, the justifications by young adults in Illinois aligned more consistently with the idea of organ donation as a gift. Based on the emphasis and prominence placed on organ donor registration in Illinois in the last decade, this is not surprising. In April of 2008, during National Donate Life Month, Illinois was completing its 18-month campaign to get 3.5 million more people registered as organ donors in the state (Donate life Illinois 2008). This campaign also followed the change in registration requirement; previously a witness was needed to sign up for the donor intent registry, but at the start of 2006 the 6 million people that registered this way had to re-register (without a witness) to be put onto the new donor list. The change in registration requirements and the push to register as a way to help the

nearly 5,000 individuals in the state of Illinois at that time that were in need of an organ transplant was circulated in the media, and large colleges in the state at a level that was unprecedented.

Young adults from Ohio, although generally understanding of the messages, questioned specifics about the short phrases presented to them. While Ohio interviewees were more critical of the short phrases, the commentary on the longer messages split between the two groups. While a familiarity with the overall message was clear and mainly positive, the use of a predominant metaphor is limiting. The Illinois interviewees were more familiar with the specific messages from their area, while Ohio interviewees also were aware of the broader metaphor of the gift. Ohioans had less exposure to it the gift as the primary message in the state, leaving them interested in more details of the process rather than complacent with the idea of an organ as a gift to help another person. Although there were some differences in exposure to state-specific campaigns in a state that has invested more effort to promote organ donor registration, the interpretation of the messages as a whole are idiosyncratic - knowledge and attitudes surrounding organ donation in the United States are variable based on individual experience. My study showed a heavy influence on young adults by sources outside of the local OPO campaign messages. These results indicated that it would be beneficial to broaden the language, details, and examples messages of not only OPO information but in media and educational platforms where young adults are more likely to engage with the topic of organ donation in their day-to-day lives. While the expansion of metaphor usage was helpful for conceptualization of organ donation, this occurs because a new message like recycling is different and potentially controversial, which provoked critical thinking about why this word would be used to describe organ transplants. If this topic encourages thought, discussion will follow. As the way most participants reported first learning about

organ donation, having more critical discussions about the topic helped to improve their understanding of the process, learn about donation stance of other people in their lives, and helped them come to conclusions about how they feel about organ donation.

One primary metaphor may not be the best way to get a group of people with different perspectives and experiences to grasp the concept of how organ donation works and what it does for individuals and society. The metaphor of the gift, thought to be a way to help others, although the metaphor may give some indication of how it is legally approached, it gave little information about how the medical process works. The metaphor of the gift gave young adults an idea of helping others but does not provide much in the way of people remembering how it was known. The idea of continuing to expand on the metaphors and general messages regularly used to promote organ donation and donor registration could be helpful. The use of the gift metaphor was familiar and did not draw as much interest to the process as the state messages that were more focuses on an aspect of donation rather than the larger project. The final message introduced a metaphor unfamiliar to all of the interviewed young adults: recycling. The agreement and comfort with its use to explain the organ donation process was mixed. Using recycling as a metaphor brought a reaction from people; some people enjoyed how it was better able to help them make sense of the process and made them want to continue to think about it and learn more, while some people were not okay with having their body being equated to trash. While the range of responses may be somewhat influence by unfamiliarity, once people thought about recycling as a parallel to organ donation resonated with many people more than referring to the concept as a gift. Recycling is a way of talking about the process of organ donation because it deviates from the standard gift metaphor, it can start a discussion of why it fits. Young adults presented with a recycling organ donation in my study were curious and many asked why it is being used and started to try and

explain its use to me and them. Some of the state phrases walked around the metaphor usage by using different phrases – to varying degrees of success – by the interest in knowing the process and getting informed on the variety of ways to discuss organ donation. A wider variety of metaphor usage can appeal to a wider range of potential organ donors, and could potentially change the way the donor decision process and discussions about organ donation, as explained further in the next chapter.

Next, I asked participants how they are thinking about organ donation after hearing the messages. Following the responses to donor registration messages, I asked the interviewees if they feel as if their knowledge of organ donation and registration has changed and if they think being an organ donor is altruistic. Overall, the most common response to alteration of personal knowledge was realizing the similar ways of presenting “gift” in national phrases. Young adults also learned different ways people end up eligible as deceased donors, the number of people in need of organ transplants, as well as the contrast in messaging focal points by the states. While minor details were gained after hearing these messages, sentiments about an individual’s stance were not changed.

While the overall response to altruism describing organ donors also was geared toward including the gift metaphor that is so familiar, there were more challenges to such a grand statement that highlight how the way in which young adults recognize their own motives. Most of the young adults interviewed in the process of this research associate organ donation with altruism. Defined as a behavior that benefits another person without any benefit for them, almost all of the young adults thought that altruism was a term that described organ donation. Of the 29 people who believed being an organ donor is altruistic, they predominantly used explanations that incorporated the gift metaphor. While most people agreed that the donor would be giving their organs and not receiving anything in return, the process referenced about in the same way it was in the first part of

the interview, as a way of helping and potentially saving people who needs organs. Eight people did not believe organ donation was altruistic, one young adult stating, "you get the benefit of knowing that you helped save someone's life" (Participant 11). Criticism of organ donation as a process that was not selfless began to show a way to improve. One interviewee even commented on bringing altruism into the conversation about organ donation made it seem negative and that talking about it in a selfless light was not as appealing as just talking about it as a decision that seemed right to them as an individual who would no longer need their own organs. One interviewee explained that they believe that "nothing is truly altruistic because there is always a deeper, selfish meaning" to a person's actions, claiming that giving your organs away after death to help others is being done "because you think it's selfless." This individual made the point that we like to think we are doing things because we are selfless, but our awareness of acts to label as selfless mean that our knowledge and label as a good person is a benefit of the action and therefore makes it selfish. Although this individual attempted to apologize for their pessimistic interpretation, they critically thought about what it means to help another person benefit while not doing so yourself. This point helps to tie in the theories of altruism and reciprocity related to gifts from Chapter 1. Although selfless behavior benefits the group rather than the individual, gifts given without the expectation of anything in return, but the expectation of reciprocity was in American society, meaning that both parties benefit. A person can give a gift to someone and not ask for anything in return, but there is a societal expectation to reciprocate and complete an exchange. Feeling the need to reciprocate a gift can apply to an organ. However, anonymity is protected in typical organ transplants, which means that reciprocation may be carried out indirectly. A transplant recipient may just be thankful for the opportunity to continue living, or they may register to be an organ donor at the end of life or donate their body in

some beneficial way as well. There are several other possible ways a person can approach the acceptance of a gift and the desire to reciprocate.

After inquiring about an individual's knowledge and exposure to organ donation, transplantation, and registration broadly and through specific messages, these responses linked the interviewees' current thoughts and decisions with the discussions and information they sought out. Young adults are most familiar with the general concepts related to the gift metaphor, but overall their focus and response to registration messages was similar to their initial idea of what organ donation is, their agreement with the practice, and their previous exposure in information about the process. While it is clear some people knew more information about the organ transplantation system, the importance of emphasizing discussion and research of donor registration messages was not clear. Knowing if and how young adults were getting additional information or having discussions would be important in potentially seeing why those sources or ideas were not seen in the messaging.

Chapter 4 – The Organ Donation and Decision System

While the previous chapter focused more on the content and reaction to the messages but the young adult interviewees, this chapter focuses on how young adults approached the decision process about being an organ donor in previous studies and in my research..

Organ Donation Decisions

Previous studies start to get at how participants articulate their understanding of organ transplants in a different light than the theory does. Studies have been done about how people understand organ donation and the decision making process. One study outlines how people misconstrue what brain death is and what they are agreeing to when they register as a donor (Shah et al. 2014: 291-296). The participants knew that brain death was an important component of consideration as a viable organ donor at the end of life, but participants did not clearly understand that brain death referred to a lack of brain activity but that the heart would still be beating. The point of greatest misunderstanding involved the transplant procedure and the removal of all the transplantable organs while the heart was still beating and then removed last (if it were being donated). While the idea of brain death being a benchmark for considering deceased organ donation, there was still misinterpretation of what deceased actually meant. The Shah et al. study showed where improvements can be made when it comes to an individual's knowledge of organ donation and transplantation when they decide whether or not to register as a donor. Another study approaches the decision making process from the perspective of the next-of-kin, analyzing how the beliefs of an individual and specifically how discussion about personal beliefs can influence another person's decision (Rodrigue et al. 2006: 190-198). The study found that organ donation was more likely when the deceased individual was young. The youth of the individual may have played a role in the overall viability of their

organs but also may have been a way for the next-of-kin to know their loved one helped other people. Donation was also more likely when the donors had made their wishes known to their next-of-kin. If the family knew the individual wanted to be an organ donor and talked about it rather than privately making indicating it on their driver's license, the family was more likely to honor the donor's wishes. If the donor had not made their wishes clear the family would often feel unsure about how strongly the donor really felt about being a donor, which resulted in fewer donors. The study helps to highlight the importance of changes to the organ donor process. One of the changes involved honoring the wishes of the donor; although the donor card was a legal document, until the 2000s next-of-kin were still able to alter the indication made by the deceased. This study also focused on the sensitivity and timing of the discussion had with the OPO coordinator, which emphasized how hard it is to talk about death even when it needed.

Overall, the findings of the previous studies were able to indicate where points of theory were present in the organ transplant process but articulated in ways that did not emphasize the detail or direct approach of the theory, but were vague. Both studies made reference to the taboo of death that was mentioned in Chapter 1 when next-of-kin did not or minimally talked to one another about their wishes concerning organ donation and how talking about a deceased individual was hard for loved ones. No one wanted to talk about death, but instead of people commenting that death is a topic that we avoid. These studies also touch on the idea of individualism from Chapter 1 when people phrase the discussion in terms of decisions and how it was the responsibility of the individual to make these decisions. However, the organ transplant system has not focused on the details associated with the broad registration as an organ donor so many details were left to next-of-kin. In fact, many of the decisions made with the narrow scope of knowledge of familial preference for organ donation, meaning the collective actually has more

influence than given credit. Unfortunately, the importance of discussion as part of the decision-making process was not clear. Other aspects of the social theory were present but diluted in their prominence; donors were referred to as whole people as well as fragmented in reference to their organs. Thinking about the body in political and biological realms was a way of forming the social body when discussing the legal and physical state of an individual. Although the theory was important for recognizing the similar themes in participant responses, the way people in the previous studies and in my own conceptualized and felt comfortable discussing the social topics associated with organ transplantation were subtle and subdued. The lack of prominent theory in participant responses results in theory being a point of comparison for how the social ideas were actually conceptualized and provides a way of discussing the topic in a way young adults do understand.

How Do Young Adults Make Their Decisions

The third and final part of the interview for this research project about the organ donor decision process young adults experience was guided by the literature outlining common ideas and concerns that factor into the decision to be an organ donor, as well as how some of these issues have already been addressed in state legislature. This part of the interview process was optional for interviewees regardless of their current organ donor status. Despite this part of the interview being optional, all 39 participants agreed to the continuation of the interview.

There were three types of questions in this section of the interview. The first type of question was concerned with the interviewee's knowledge about organ donation:

- How familiar/confident were you with the ideas of/ your knowledge about organ donation before you were asked to register for the first time?
- Did being prompted about registration as an organ donor result in a search for

further knowledge on the process? If so, what were you interested in learning about?

- What are your biggest concerns about how the organ donation process works?

In this part of the analysis of participant responses it was important to distinguish between the actual knowledge participants had compared to how they felt about the information they knew at that point. A participant's feelings about their knowledge base are significant when thinking about if they feel okay making the decision about being an organ donor with limited information or not. The interviewees described what they knew about organ donation. I asked about their knowledge in connection to the actual time and experience when approached about organ donation. The responses indicated that while most people were not confident about their knowledge about the entirety of the organ transplantation process, most of the interviewees were confident in their registration decision. For example, Participant 8 "knew the basics and that was enough" for registration, though the individual knew that they did not understand everything about organ donation. Frequently, even when young adults only knew the bare minimum about organ donation, the idea that it was helping people once they were dead themselves was very positive.

When it came to having information, five people were not comfortable making the registration decision until they had more information about the process; Participant 3 had dealt with "not having enough information at the age of 18" but felt confident enough to register at 21 even though the participant has not sought out additional information. Three young adults did not feel capable of making the decision when initially prompted as teenagers, but had since decided to register when they renew their license. However, most people knew they were missing details about organ donation, yet only two actively explored the topic on their own.

Participants were most concerned about the medical and procedural details of a transplant. Young adults wanted to know “how the organs are tested and matched” as well as how the operation works on the medical side (Participant 21). Several of the young adults were concerned about how their body would look after the operation and “how it would influence their funeral” (Participant 1). Two people expressed an interest in learning about the legal procedure required for a donation to happen.

The second type of question was concerned with the discussions interviewees had about organ donation before and after they prompted about organ donor registration:

- Did you consult with anyone or anything before being prompted to register to be an organ donor?
- Did you feel as if you needed to talk to anyone before being asked about donor registration?
- Did you feel the desire or need to tell someone about the decision you made? If so, did you actually do so and who was it?
- Is there a person or people in your life that are aware of your feelings about organ donation? If so, do they support your decision? Do they hold similar ideas themselves?

Based on the first time the young adults remembered being asked about organ donor registration, only seven participants consulted with a family member. The conversations were similarly described as being very brief conversation that “came about naturally” rather than in the pursuit of an opinion by the young adult (Participant 7). The lack of interest in gaining information about organ donation before registration was supported by the disclosure that only two young adults actively sought out other people to ask about registration.

Following the pattern of minimal communication, only a few interviewees felt the desire to tell anyone else about the decision they made about organ donation. When people did feel compelled to mention organ donation it was also connected to mentioning

their license. Talking about organ donor status happened mostly to “mom, dad, and siblings” (Participant 4).

The last question of this section ascertained that a majority of the young adults had at least one person in their life who knows how they currently stand when it comes to being an organ donor. While most of this knowledge exchange occurred right before or right after registration, such as “in the car on the way to the DMV” (Participant 17). The discussion was usually very limited in terms of discussion, not going beyond the reiteration of the organ as a gift and that this was a good and helpful act. There were not major differences in the number of registered and unregistered organ donors between regions. It was interesting to find that most of the young adults talked about having the same or similar views as their parents and other family. The alliances still stuck for a few individuals that actually had different views than their family but did not want to “start anything” (Participant 5). This point raised questions about the claim and ownership of an individual, specifically the say of a parent on how a mature adult child uses their body. How common is this expectation of the self being influenced by others happening when it comes to organ donation and other situations? Does this make the decision and process easier?

The last type of question was actually the last question of the entire interview:

- Do you have any other ideas, feelings, or stories about your personal experience concerning organ donation that you would like to discuss?

The responses to this question were a good representation of the idiosyncratic experiences and interpretation of organ donation and registration. People from both regions elaborated on how their families had a strong influence on their registration decision. Some young adults would justify their decisions and said they were okay with not being a donor because it made them “nervous,” and a couple others were only doing

it out of respect and not wanting to cause any tension (Participant 13). Some of the other personal experiences brought in perspectives from other donation situations, with one interviewee who consistently donates blood and another who knew about a family member receiving a kidney from a living donor. Ultimately, this question provided a platform for elaboration on some education, conversation, or phrase that the interviewee had not remembered before.

Overall, complete participation in the optional portion of the interview provided general information about the young adult participants. Although all the interviewees appeared happy enough to help, most of them gave either very brief responses that only consisted of a word or phrase, and some gave long, detailed stories. The discrepancy in material could be indicative of which individuals had more information or had a deeper conversation or experience with organ donation. However, the level of active participation in the interview may also be indicative of the participant's comfort level with discussing organ donation, medical procedures, or death.

Conclusion

This research project set out to discover how young adults understand the organ donation and transplantation process. I collected interviews in the Chicago and Cleveland areas from young adults about what they know about organ donation, how they comprehend donor registration messaging, and how they have approached the discussion and decision-making process about registering as an organ donor. From these interviews, I found that young adults perceive organ donation as a positive process, but many are not receiving the donor registration messages geared towards them and have found that they are unable to make informed decisions about registration.

Research Questions

This research project broadly began with the question of how does the deceased organ transplant system work in the United States and why is there a standard way of referring to and talking about organ donation as something one individual can do to help another once they're life can no longer go on. In order to have a baseline for conceptualizing ideas about organ donation I looked to social theory. Scheper-Hughes provided one way of viewing the body in parts and as a commodity. Although it was helpful to grasp the value placed on the human body over time and specifically in light of organ transplantation, it was interesting to see how this theoretical comprehension related to the way in which young adults conceptualize and refer to organ transplants. Similarly, Mauss's discussion of gifts offered a way of understanding social exchange, but the young adults only mentioned gifts and did not acknowledge how this act was a demonstration of social exchange. Most points of theory that grounded the concepts talked about (and avoided) by young adults were helpful to recognize ideas and patterns, but ultimately they did not refer to the ideas by name, such as commodity, fragmentation, reciprocity, Cartesian-dualism, or the taboo of death. While it was important to introduce

the theoretical concepts as a way of showing how previous research has focused on organ transplantation in the United States, comparing those ideas with the ideas of young adults shows the differences in addressing organ transplants. For example, while it is clear that the young adults I interviewed knew that human organs have value as a way of aiding another person's life they did not refer to organs as commodities. While the young adults knew conceptually that being an organ donor could help several people because each organ could go to a different person, they did not dwell on the fragmentation of their body, only sometimes mentioning the idea when saying that a part of them would be used. The same goes for altruism and reciprocity, the young adults referred to an organ as a gift or donation but rarely reflected on what it meant for the donor's role or how the recipient could potentially give repayment until prompted by the interview questions. Once the participants answered, it was clear that many of them held the idea of being a selfless act or that repayment was a daunting, if not impossible, task. These theoretical ideas were not at the forefront of most of the young adults' minds, but some essence of their social influence remained. Comparing theory related to understanding organ transplants and how young adults actually talk about organ transplants indicated how the ideas were referenced in broad terms or how the lack of mentioning them were just as important as a way to show these ideas are actually present. The way young adults talked and relayed their knowledge about the donor process showed general discussions of the theoretical concepts. Knowing how those ideas are referenced and related to one another by the population making decisions about their place in the system could lead to messages and information that frame information using the language young adults already have for organ donation to address the components of the system in broad terms.

With my research, I was able to address how medical advancements lead to the possibility of organ transplants from one person to another, and how this process resulted

in the creation of an organ exchange system. I was able to learn how our society has created an organ shortage by establishing a system that relies on this newfound ability to prolong life through putting another person's vital organ into someone whose own organ is not properly functioning. More specifically, I also looked at two different regional areas to see how young adults viewed being an organ donor as an altruistic act, the different conceptualizations of national and state registration messages, and how more goes into the decision to register as a donor than just agreeing that the concept of organ transplants as a good thing.

Organ Donation: What Young Adults Know, Message Influences, and the Decision

From my initial questions about the formation of the organ transplant system and its function in the United States, my research project took shape from the hypothesis that if a young adult understands the intended metaphor used in language or campaigns concerning organ donation, then that information will inform their position about registering as a donor. While the interviews show the comprehension and commentary of registration messages was an indicator of an individual's stance as a donor, exposure and information from other aspects of life such as family, educational courses, and media frequently and extensively were referenced as influential on their organ donor status decision.

From the first part of my data collection, the most informative results focused on what the young adults knew about organ donation and where they remember getting ideas about organ transplantation. The general knowledge interviewees offered about what they knew about being an organ donor was typically vague and brief; interviewees broadly talked about it being a way to give your organs to someone else once you are dead and indicated as a donor on your driver's license. Mentioning the registration process is important to knowing that there is a system in place for organ transplants and that signing

up is an important step, but only some people mention this, while other aspects of the system such as the legality and medical changes and approval that is also important.

The second part of my data collection was most informative when it came to evaluating the over-simplified and/or ambiguous messages that are in use today. The messages specifically mentioning the gift were broadly familiar to the young adults, while most of the other messages aside from “life goes on” were not familiar. Young adults most enjoyed the longer national messages that made them feel as if they were walking away with some new piece of information, even if it was small. The interviewed group ended up being split in their sympathy and interest of the Illinois and Ohio state message; some people enjoyed the brief phrases, while others found them bothersome because of the lack of clarity in the message. While it was obvious that the young adults were familiar with the language of “help,” “save,” and “hope” connected to the gift metaphor for decades; mixed feelings persisted about the use of these ideas by the young adults I interviewed. For many young adults it was clear that the gift metaphor was what they knew and was comfortable with, for many the frustration of the vague use of the metaphor was not helpful. When comparing the gift metaphor with the recycling metaphor, there was a split in preference. While more of the young adults interviewed still preferred the gift metaphor messages, several participants immediately connected to the idea of recycling as a way to communicate about organ donation. From this section of the interview it was clear that the region did not influence knowledge of concepts or familiarity of messages but on clarity of comparison and idiosyncrasies in a person’s experience. Some young adults found a clear comparison of the systematic organization of recycling with the systematic preparation of having a successful organ donation, when recycling benefits society and parallel the larger national organ system rather than an individual getting the organ. In addition to improvements that a recycling metaphor can

make to some young adults thinking about the process of organ donation, previous personal experience such as education, media exposure, and interpersonal communication can influence a young adult's interest and knowledge of different aspects of the organ donation system. Therefore, expanding on the language and metaphors used allowed for some of the young adults to make better sense of and pay attention to organ donation messaging.

The third part of my data collection looked at how young adults approached the decision to register as an organ donor. The organ donation data gathered included how confident they felt in their knowledge about it, if they sought out information, if they talked to people about it before and after they were asked about registration, and what they don't know about the process. Young adults wavered in their confidence and knowledge about organ donation, yet almost none of them sought out additional information. While many of the interviewees have had conversations with family or close friends about their organ donor status, these conversations were usually brief in both time and detail, most people could not recall what the content of the discussion. While it was good that most of the interviewees had at least one person that knew about their donation wishes, the fact that detailed conversations were almost nonexistent was not okay in the long run. Although improvements were made so donor wishes could be respected and harder for the next-of-kin to alter, having an open dialogue and a detailed conversation about the recognition and tolerance of the process was still one of the most important parts of the a young adult's decision to be an organ donor. The next-of-kin still had to handle many details if something were to result in a deceased donation, so being informed and having someone that supports the views of the donor was important.

Connecting the three steps of young adult comprehension of the organ transplant system in the United States can benefit the continuation and success of the system.

Knowing that the gift metaphor was predominantly used as a way of communicating about organ donation was substantial, but learning that many gift-related metaphor messages on a state level, where the most interaction should be happening, was ambiguous does not help to further the detailed functioning of the system. The fact that many young adults initially received information about being an organ donor in the form of a brief discussion with their parents at a young age resulted in the knowledge of their parents' perspective but a lack of enthusiasm to learn about it on their own. Young adults also learned about organ donation through formal education in driver's education, science or ethics classes as well as media sources like movies, television, and social media. The greater breadth of knowledge from multiple systems expanded the possible perspectives from which young adults can best take in ideas about organ donation.

The current standard of organ donation knowledge has been falling short. Although made to increase registered donors, campaigns have not provided young adults with the knowledge outside of the broad definition and an indication on a driver's license is not adequate to having people properly informed about the U.S. system of organ transplantation. Messages have also not helped young adults understand how different parts of the metaphors about organ donation actually relate to parts of the system from a medical and legal perspective or how discussions and support can lead to increased comprehension of the topic and preparation for dealing with a donation situation if it becomes necessary. Gaining knowledge through discussion, education, and media content can improved as sources of information about organ donation. Ultimately expanding the metaphors used to relay donor registration ideas could aid in catching the attention of young adults in the Chicago and Cleveland areas. Information has been available from multiple sources, showing the traditional national or local OPO campaigns, some grounded in morals and ethics with discussion, and some were more scientifically robust

in a classroom setting. However, expanding on the explanation of organ donation on a national level could allow other effective ways of talking about donation to permeate into the areas of society that the current gift metaphor has already. Including recycling as a way to think about organ donation has the potential to reach more people than the current messaging does, because recycling was a controversial way to talk about organ transplantation and the metaphor could act to parallel more aspects of the donation process. Using recycling as another way to portray organ donation can spark a discussion. Not only will this be a new way of talking about organ donation, but the fact that even within two regions of the country there are different reactions to it will people's attention and encourage a new conversation.

Although getting a better idea of what young adults thought and talked about organ donation, which does not mean that it would be easy to change how comprehension happens. With the use of recycling, the view of the decision to be a donor as a primarily independent decision when discussion and their involvement actually contributing to a larger system will take time. Just because recycling could be a better way for a person to conceptualize how organ donation works, does not mean that every single person will, or that for everyone it will be a personally beneficial way to talk about death. This research project only began to look at the ways in which young adults are thinking and talking about organ donation and can be expanded. My project looked at young adults ages 18-29 in the Cleveland and Chicago area, so further research could focus on expand on the OPO regions and age range a better idea of how information and discussion is happening. The expansion of metaphor usage could alter the way organizations create messages about organ donation, and have the ability to continue influencing how young adults understand the value given to body parts and how they conceptualize decisions about these values.

References

- Abouna, George M. 2008. "Organ shortage crisis: Problems and possible solutions." *Transplant Proceedings* 40(1):34-80. doi: 10.1016/j.transproceed.2007.11.067.
- Bauman, Zygmunt. 1992. *Mortality, immortality and other life strategies*. Cambridge: Polity Press.
- Ben-David, Orit Brawer. 2005. *Organ donation and transplantation: Body organs as an exchangeable socio-cultural resource*. Westport, Connecticut: Praeger Publishers.
- Coad, Laura, Noel Carter and Jonathan Ling. 2013. "Attitudes of young adults from the UK towards organ donation and transplantation." *Transplant Research* 2(9). doi: 10.1186/2047-1440-2-9.
- Csordas, Thomas J. 1994. *Embodiment and experience: The existential ground of culture and self*. Cambridge: Cambridge University Press.
- "Donate life America". 2016. Donate Life America. Retrieved April 7, 2016 (<http://donatelife.net/>).
- Donate life Illinois. 2008. "Illinoisans called upon to register as organ & tissue donors in final push to reach campaign registration goal." Retrieved: April 7, 2016 (<http://www.prnewswire.com/news-releases/illinoisans-called-upon-to-register-as-organ--tissue-donors-in-final-push-to-reach-campaign-registration-goal-56956602.html>).
- "Donate life Ohio". 2016. Ohio Department of Health. Retrieved April 7, 2016 (<http://donatelifeohio.org/>).
- Douglas, Mary. 1984. *Purity and danger: An analysis of the concepts of pollution and taboo*. New York: Routledge.

- Douglas, Mary. 1996. *Natural symbols: Exploration in cosmology*. London: Routledge.
- "Dying in America: Improving quality and honoring individual preference near the end of life." 2014. Washington DC: Institute of Medicine of the National Academies.
- Goila, Ajay Kumar and Mridula Pawar. 2009. "The diagnosis of brain death." *Indian Journal of Critical Care Medicine* 13(1):7-11. doi: 10.4103/0972-5229.53108.
- Hedges, Stephen and William Gaines. 2000. "Donor bodies milled into growing profits." *Chicago Tribune*, May 21. (http://articles.chicagotribune.com/2000-05-21/news/0006170024_1_usable-tissue-body-parts-national-organ-transplant-act).
- Hirschauer, Stefan. 1991. "The manufacture of bodies in surgery." *Social Studies of Science* 21(2):279-319.
- Journal of the American Medical Association. "A definition of irreversible coma: Report of the ad hoc committee of the Harvard Medical School to examine the definition of brain death." 1968. Vol. 205(6):337-340.
doi:10.1001/jama.1968.03140320031009.
- "Life goes on - Illinois organ/tissue donor program". 2016. Life Goes On. Retrieved April 7, 2016 (<http://lifegoeson.com/>).
- Lock, Margaret. 2002. *Twice dead: Organ transplants and the reinvention of death*. Berkeley: University of California Press.
- Mauss, Marcel. 1954. *The gift: Forms and functions of exchange in archaic societies*. Gelencoe: The Free Press.
- Morgan, Kathryn Pauly. 1991. "Women and the knife: Cosmetic surgery and the colonization of women's bodies." *Hypatia* 6(3):25-63.
- Nelkin, Dorothy and Lori Andrews. 1998. "Homo economicus: The commercialization of body tissue in the age of biotechnology." Vol. 28. *Hastings Center Report*.

- "Organ donor registry: US government information on organ donation and transplantation". 2016. US Department of Health and Human Services. Retrieved April 7, 2016 (<http://www.organdonor.gov/>).
- Patterson, Orlando. 1982. *Slavery and social death: A comparative study*. Cambridge: Harvard University Press.
- "Recycle yourself". 2016. Donate Life America. Retrieved April 7, 2016 (<http://gorecycleyourself.com/about-donation/recyclable-body-parts.php>).
- Richardson, Ruth and Brian Hurwitz. 1987. "Jeremy Bentham's self-image: An exemplary bequest for dissection." *British Medical Journal* (295):195-98.
- Rodrigue, J. R., D. L. Cornell and R. J. Howard. 2006. "Organ donation decision: Comparison of donor and nondonor families." *American Journal of Transplantation* 6(1):190-98. doi: 10.1111/j.1600-6143.2005.01130.x.
- Scheper-Hughes, Nancy and Margaret Lock. 1987. "The mindful body: A prolegomenon to future work in medical anthropology." *Medical Anthropology Quarterly* 1:6-41.
- Services, U.S. Department of Health and Human. 2016a. "Organ procurement and transplantation network: Regions": Health Resources and Services Administration. Retrieved April 7, 2016 (<https://optn.transplant.hrsa.gov/members/regions/>).
- Services, U.S. Department of Health and Human. 2016b. "Organ procurement organizations": Health Resources and Services Administration. Retrieved April 7, 2016 (<http://www.organdonor.gov/materialsresources/materialsopolist.html>).
- Services, U.S. Department of Health and Human. 2016c. "Timeline of historical events significant milestones in organ donation and transplantation": Human Resources

- and Services Administration. Retrieved April 7, 2016
(<http://www.organdonor.gov/legislation/timeline.html>).
- Shah, Seema K. 2014. "A narrative review of the empirical evidence on public attitudes on brain death and vital organ transplantation: The need for better data to inform policy." *Journal of Medical Ethics* 41(4):291-96.
- Scheper-Hughes, Nancy and Loic Wacquant, eds. 2002. *Commodifying bodies*. Thousand Oaks, California: SAGE Publications.
- Solomon, Steven. 1987. "Spare parts for humans." *Forbes*, pp. 52-54.
- Stickney, Melissa A. W. 2002. "Property interests in cadaverous organs: Changes to Ohio Anatomical Gift Law and the erosion of family rights." *Journal of Law and Health* 17(1):36-75.
- "The advancement of organ transplantation". 2016. Transplant Village. Retrieved April 7, 2016 (<http://www.transplantvillage.org/the-advancement-of-organ-transplantation/>).
- "The Facebook Effect: Social Media Dramatically Boosts Organ Donor Registration." 2013. Retrieved: April 7, 2016
(http://www.hopkinsmedicine.org/news/media/releases/the_facebook_effect_social_media_dramatically_boosts_organ_donor_registration).
- "The Gift of a Lifetime: Organ and Tissue Transplantation in America". 2016: Fusionspark Media. Retrieved April 7, 2016 (<http://organtransplants.org>).
- Turner, Terence. 1994. "Bodies and anti-bodies: Flesh and fetish in contemporary social theory." Pp. 27-47 in *Embodiment and experience: The existential ground of culture and self*, edited by T. J. Csordas. Cambridge: Cambridge University Press.

"United network for organ sharing". 2015. United Network for Organ Sharing. Retrieved April 7, 2016 (<https://www.unos.org/>).

Walter, Tony. 1991. "Modern death: Taboo or not taboo?". *Sociology* 25(2):293-310.
doi: 10.1177/0038038591025002009

Wendler, David and Neal Dickert. 2001. "The consent process for cadaveric organ procurement: How does it work? How can it be improved?". *JAMA* 285(3):329-33.

Appendix

Young adult participant identification numbers

Participant ID Number	Region Participant is From
1	Chicago
2	Chicago
3	Chicago
4	Chicago
5	Chicago
6	Chicago
7	Chicago
8	Chicago
9	Chicago
10	Chicago
11	Cleveland
12	Cleveland
13	Cleveland
14	Cleveland
15	Cleveland
16	Cleveland
17	Cleveland
18	Cleveland
19	Cleveland
20	Cleveland
21	Cleveland
22	Cleveland
23	Cleveland
24	Cleveland
25	Cleveland
26	Cleveland
27	Cleveland
28	Cleveland
29	Cleveland
30	Chicago
31	Chicago
32	Chicago
33	Chicago
34	Chicago
35	Chicago
36	Chicago
37	Chicago
38	Chicago
39	Chicago