

DISSERTATION

ORGAN DONATION AND THE TEENAGE PERSPECTIVE:  
FACTORS TO CONSIDER REGARDING CONSENT

Submitted by

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## ABSTRACT

### ORGAN DONATION AND THE TEENAGE PERSPECTIVE: FACTORS TO CONSIDER REGARDING CONSENT

The purpose of this study was to understand the factors that teenagers consider when granting consent to become an organ donor for the first time. Ninety-seven participants completed a 31-item survey that included areas of knowledge, source of information, personal experience, willingness, and consent. Least square means and Chi-square were used to compare groups (e.g., experimental/control, pre-survey/post-survey) regarding consent. Other variables that were explored included; gender, ethnicity, religion, grade point average, and parent level of education. The intervention consisted of basic information regarding organ donation, a video entitled *No Greater Love*, and small group discussion regarding various donor/recipient scenarios. Findings indicated that increased knowledge does not always lead to consent, nor does knowing a donor (living or deceased) or someone on the waitlist influence consent among adolescents. The results suggested that teenagers do not have a good understanding of the topic of organ donation nor do they see themselves as living donors. Teens may not fully understand the implications and ramifications of their decision to be a donor when receiving a driver's permit or license for the first time. This study brought to light factors that teens take into consideration when deciding to become an organ donor.

## ACKNOWLEDGMENTS

This journey began for me at a very early age, an age when I did not fully understand what earning a doctorate degree meant. Throughout my life there have been people or events that have shaped who I am today, and for that I am deeply grateful. This process has been very humbling and has reinforced just how much I still have to learn. This is clearly a situation where the journey is more important than the destination. I must begin by saying “thank you” to my uncle Paul, without your major contribution I would have never obtained this accomplishment—Thank you, and Thank you for your constant prayers!

I will never forget the day my parents found out that I was working on my doctorate, my dad pretended to have a heart attack, and my mom cried. Although my dad did not attend college, he is one of the smartest people I know. My mom once told me that you can live in a big fancy house and drive a shiny new car, but those things can be taken away from you . . . she would say that no one can ever take away your education . . . she was absolutely right.

My husband and children who I have truly been blessed with and whom I love dearly were encouraging and supportive in their own unique way. I find their humor to be both inspiring and alarming. They often got me off task, yet helped me keep things in perspective. Attempting to earn this degree with two high school/college students in the house was a challenge and a motivator. I can’t count the number of times I had to ask them some computer-related question, how to insert a table, or how to format something. Jeff, “thank you” for your patience and support throughout this process—I love you dearly! Hannah and Dylan, I am so extremely proud of both of you for the awesome young adults you are becoming. I hope the two of you always stay close, and I hope you can always see the value in the struggle and in hard

work. Don't ever let someone tell you that you can't do something!! You have many talents and gifts--use them, and remember to stay true to yourself. "I love you both so very much!"

To my committee members, who have been supportive, thank you for your time, encouragement, and recommendations. Vicky, I so appreciate everything that you have done for me. I know that these past few years have been difficult for you, but I always felt that I could come to you, and I really appreciate all the time you spent with me. Carole, what can I say, you are a dear soul, and I really don't think I could have done this without you, you have my deepest respect. I appreciate your helpful comments, your positive and encouraging presence, and the many laughs we had in class. To Jim, thank you for taking time for me, for running the stats and for helping me interpret them, I greatly appreciate you!

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## DEDICATION

This work is dedicated to my dear grandma Charlie who I miss very much and still think of often, she was the initial reason I wanted to earn my degree. She always believed in me and told me that I was smart, told me I could earn my degree with hard work. On numerous occasions when I doubted myself throughout this process, I thought of Grandma Charlie. It is in her honor that my childhood dream became a reality. I like to think that she would be very proud of me.

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## LIST OF ACRONYMS

### Acronyms Used in Study

AIDS: Acquired Immunodeficiency Syndrome

CDD: Circulatory Determination of Death

DMV: Department of Motor Vehicle

HLA: Human Leukocyte Antigen

HRSA: Health Resources and Services Administration

IOM: Institute of Medicine

NDD: Neurological Determination of Death

NOTA: National Organ Transplant Act

OPO: Organ Procurement Organization

OPTN: Organ Procurement and Transplantation Network

PSDA: Patient Self Determination Act

PWM: Prototype Willingness Model

SNS: Social Network Sites

UAGA: Uniform Anatomical Gift Act

UNOS: United Network for Organ Sharing

USDHHS: U. S. Department of Health and Human Services

## REMEMBRANCE

In Loving Memory of Patricia Dicamillo Iverson

1970-2013

“May the choir of angels come to greet you, may they speed you to Paradise, may the Lord enfold you in His mercy, may you find eternal life . . .” May you see the grace of God, and may you have eternal peace.

—I miss you.

# CHAPTER 1

## INTRODUCTION

Organ donation is the act of a healthy person (organ donor) giving an organ to another person (recipient) in need of a healthy organ. For some organs, the donation can be given while the healthy person is alive—in other cases, the donation is made at death. Historically, organ donation has been looked upon as a compassionate and charitable act. The most frequently transplanted tissues are corneas, long bones (arms, legs), heart valves, and skin, according to medical personnel J. Welsh (personal communication, June 17, 2011). Tissues, stem cells, and blood can also be donated.

People may have different views of organ donation based on the type of donation or the manner in which it is handled. For example, some may approve of donating blood or plasma, while others may see this as painful, intrusive, or time consuming.

### **Blood and Plasma Donation**

Blood donations are needed for emergencies (e.g., tragic events or accidents) and transfusions. Approximately 14 million units of blood are donated each year in the United States (Healy, 2006). J. Welsh, medical professional, (personal communication, June 17, 2011) states that 1-5% of the population donates blood. According to M. Webb at the Garth Englund Center in Fort Collins, Colorado, a blood donation center; a blood donation takes 30-45 minutes and approximately one pint is retrieved (personal communication, June 6, 2013). One can donate only every eight weeks (56 days) without receiving payment. Most blood is processed and delivered safely to recipients; however, in the early 1980s, fear spread through society when the



first documented case of Acquired Immunodeficiency Syndrome (AIDS) was found to be transmitted through a blood transfusion (Healy, 2006).

Plasma is used for those with immune deficiencies, clotting disorders, and burns. The process for donating plasma is similar to donating blood. With a plasma donation one is hooked to a machine that divides the blood and the plasma (fluid or liquid part of the blood), with the red blood cells returned to the individual. With a plasma donation, one can donate twice a week with one day in between donations. Individuals who donate plasma are financially compensated based on their weight. Even this simple type of donation can create strong opinions or controversy. Is it really a donation if one is gaining payment? And, if one is paid for donating plasma, why is one not paid for donating blood?

According to the local plasma center, CSL Plasma (personal communication, June 9, 2013), there are 78 plasma donation centers across the United States. The six Commonwealth Serum Laboratory plasma agencies that were contacted are all within two miles of a major college or university. With such prime locations and the incentive of payment, college students may be a targeted population for donation. Each year approximately 20 million liters (worldwide) of plasma are used for various therapies (Plasma Donation, 2013).

### **Organ Donation**

Solid organ donation occurs when a living or a deceased donor chooses to give one or more of their organs for the purpose of benefiting or saving the life of another. The procedure in which this happens is an organ transplant or transplantation.

People have different views of blood and tissue donation than of solid organ donation (liver, heart, etc.). When one has to endure possible physical pain or risk or if there is no perceived gain, one may be less likely to give of themselves. With the introduction of the

concepts of life and death, a donation in which lives may actually be saved is quite different than a blood or plasma donation. Would you choose to save or extend someone's life if you could? Or, would you agree to have your loved one save someone's life if he or she could?

### **Societal Views**

The majority of the general public is in favor of organ donation (Gallup Organization, 1993; Siminoff, Gordon, Hewlett, & Arnold, 2001). Radecki and Jaccard (1997) found the general public has a positive attitude toward organ donation and slightly more than one-fourth of people actually signed some form of a donor card. More recent research (King, Williams, Harrison, Morgan & Havermahl, 2012) found that approximately 90% of the general public was in favor of donation, while 30% were registered donors. However, consent for organ recovery continues to be a crucial barrier for individuals and families.

Youngner (1990) suggests that society is actually hesitant about organ donation and in the abstract, it is valuable; but when applied personally, individuals find it distasteful. There is mistrust and confusion on part of the general public regarding organ donation. People want to believe and know this process to be trustworthy and fair. Today, people still find the subject somewhat unpleasant and there has been little change in the total number of donors in the last 10 years (Carey & Gonzales, 2015). In all cases, the dead donor rule must prevail. This rule basically states that organs may not be procured until the person has died (Institute of Medicine (IOM), 2006). Some mistrust may come because of the two definitions or criteria for death. The first is neurological determination of death (NDD), formally referred to as brain dead. This implies that there is no brain function or activity.

The second definition of death is circulatory determination of death (CDD). This implies that one's heart has stopped beating (IOM, 2006). Confusion and mistrust may stem from the

fact that not everyone involved in a case is working from the same premise or definition. Donors, donor families, and medical professionals may have differing views of what actually constitutes death.

To better understand how the public defined brain death, Dubois and Schmidt (2003) conducted a telephone survey, with results indicating that 84% of heads of households considered one to be dead if the breathing was being mechanically supported, while 60% of heads of households believed one to be dead if the heart was beating with no brain activity. According to researchers (Dubois & Anderson, 2006; Pearson, Bazeley, Spencer-Plane, Chapman, & Robertson, 1995; Siminoff, Mercer, & Arnold, 2003), the doubt surrounding whether a person who is determined to be neurologically dead is actually dead may affect the willingness of family members to grant consent to donate their loved one's organs.

Some believe that the confusion regarding NDD and CDD would be alleviated or eliminated if donation was separate from the definition of death (Truog, 1997; Youngner & Arnold, 1993). This concept means that organs could be recovered from an individual once life support was discontinued even if the patient was not dead (IOM, 2006). In some situations, a heart can continue to beat for hours after a patient is disconnected from mechanical support equipment. Without sufficient oxygen and blood flow to organs, these possible donors may no longer have viable organs. This concept is in direct violation of the dead donor rule and may intensify distrust people have toward organ donation and medical professionals (IOM, 2006). Some may see this as euthanasia. Although one could argue that this may be one way to increase available organs, it clearly would have extreme moral and ethical ramifications.

In situations where there is heightened emotion, such as organ donation, people expect others to be ethical and abide by societal norms. Whether individuals agree or disagree with

organ donation, grant or do not grant consent, the hope is that the general public becomes aware of the issues that surround organ donation.

### **National and State Facts**

One individual donor can save up to eight lives through solid organ donations alone and up to 100 lives with blood, tissue, and solid organs (“Why Donate,” n.d.). In 2013, approximately 121,000 people, nationally, were waiting for organ transplants. On average, 245 people are added to the waiting list every month, and 18 people per day (6,570 per year) die due to a lack of available organs. In 2012, there were 8,127 deceased donors and 6,017 living donors, resulting in 28,535 organ transplants (Donate Life Colorado, 2013).

While most organ transplantations occur after brain death, only 1-4% of these deceased are considered to be potential organ donors (Pierini et al., 2009). With such a low percentage of people being potential donors, one can begin to see there are few circumstances favorable to waiting recipients.

It is well documented that the number of individuals waiting for organ and tissue transplants (demand) vastly exceeds the number of donated organs (supply). Another source reports that every 11 minutes another name is added to the waiting list (“About Donation and Transplantation,” n.d.). Colorado has one of the largest donor registries; based on the state registries, 67% of adult Coloradoans are donors. Over 2,700 people in Colorado and Wyoming are on the waiting list; of those, 1,621 are waiting for a kidney (73%), which is the most-needed organ. Forty-six percent of people on the waiting list are between the ages of 50-64 (Donate Life Colorado, 2013).

### **Theoretical Frameworks**

The conceptual framework or lens in which this study was viewed consisted of three theories or models, Bronfenbrenner’s ecosystems, Erikson’s psychosocial stages of development,

and the prototype willingness model. These three theories or models appropriately explain or describe what teenagers may be experiencing when asked to become an organ donor for the first time.

## **Ecosystems**

According to Bronfenbrenner's ecological systems theory (1979), individuals interact with their environment on five levels and are influenced by various systems at each level. The levels include microsystems or features in the immediate environment; for example, teens are influenced by family and friends, based on family traditions, values, religion, school groups, and peer pressure. Mesosystems are links between settings (home and school), such as relations among teachers and parents and coaches and parents. Exosystems are environments where the individual (teen) is not directly influenced, such as the adolescent and his or her parent's coworkers (work place) or friends. Macrosystems, are the combination of the previous three systems and, represent characteristics of a subculture, and lastly, chronosystems, are the change and consistency of daily life (changes in family structure, empty nest, jobs, residence, routines, hobbies, etc.) (Appendix A). Other researchers (Little, Bovaird, & Card, 2007) have similar thoughts as Bronfenbrenner, suggesting that teens of today are still influenced by their immediate environment, indicating the theory of ecosystems is a viable theory.

Many of the interactions teenagers have with each other are through the world of technology. This provides both advantages and disadvantages. For example, with all the social network sites (SNS) to which teenagers have access, they may miss a week of school and still know who broke up with whom, what the homework is, and bully each other from afar. People post information they choose to post.

According to Ahn (2010) characteristics of friends relates strongly to how one is perceived. Research (Donath & Boyd, 2004) indicates that SNS offer a stage for teenagers to develop and display their personal and social identities. Ahn (2010) found teenagers who access SNS report significantly higher levels of social importance than their peers who do not. Although there may be a lot of interacting among adolescents on SNS, they are missing out on the true benefits of face-to-face verbal conversations and opportunities to connect and build relationships with each other. Instead, they harass and break up with each other with a text message and other social media avenues. Cell phones are no longer used to call to talk to someone, but instead, are used to avoid social interactions. Social network sites provide interactions from a peripheral view; this is important to consider when looking at the ecosystem of teenagers. Perhaps SNS provide a world of technology where the family unit is less valued or less influential, or perhaps it keeps us connected to our friends and family on a more regular basis. Regardless of the methods in which teenagers interact, face-to-face and through technology, at some point, their immediate environment (parents) takes a back seat to other systems (peers) that influence them more.

## **Development**

There are various human developmental theories that could be reviewed, but I will focus on Erik Erikson's psychosocial stages of development, which include eight stages (Appendix B). In each stage, one is challenged with a crisis that leads to opposing outcomes. At each stage, individuals are faced with mastering a task. Mastery of stages or tasks does not have to be in a specific order, and one does not have to master a stage before approaching the next one; however, if one does not master a stage or task, the struggles and opposing feelings present with each stage may manifest themselves in future situations (Erikson, 1963).

According to Erikson (1963), a teenager's development falls into the conflict of identity versus role confusion. At this stage, they are consumed with how they look, how they are perceived, and how they fit in at home (scapegoat, peacemaker, etc.), at school (jock, nerd, etc.), and in society in general (career). Because peers are so important at this stage, adolescents can experience peer pressure and be either positively or negatively influenced by their peers.

Erikson (1963) states the conflict may lead teens to ask themselves who or what they identify with. Because adolescents often see themselves as being invincible, the struggle with role identity in regard to organ donation may be that they do not see themselves as a donor or may have a difficult time thinking about their own death, or the death of another, especially one of their own age.

### **Decision Making**

One cognitive theory based on decision making is the prototype willingness model (PWM). The theory states that one's intentions are influenced by attitude. If one has a positive attitude toward something, they will be more likely to act (Hyde & White, 2010). The theory speaks to normative belief or subject norms.

**Prototype willingness model.** The premise of this model is that decision making is impulsive and hasty, without pondering long-term outcomes. One is merely looking at the situation or the factors involved at that moment (Gibbons, Gerrard, Blanton, & Russell, 1998). In these situations, there is an element of risk taking that may be attractive to some. Because perception of the direct situation (in this case, the decision to become an organ donor) has to always be taken into consideration, many people often have an immediate reaction (positive or negative) to a situation. Interpretation of the situation may vary from person to person. Basically, the choice is a yes or a no response.

The factors of this model include willingness to participate (based on attitude), subjective norm (perceived pressure from others to do the right thing), past behavior, and the person or the prototype of the behavior (the model or the image of the person that performs the behavior; i.e., organ donor) (Hyde & White, 2010).

Although the PWM has been used with a variety of health-related behaviors and issues (Rivis, Sheeran, & Armitage, 2006), it has not been utilized with altruistic behaviors, specifically organ donation. Teenagers are asked if they consent to become organ donors at the Department of Motor Vehicle and are expected to make a quick decision; this theory and the elements of this theory may be what contributes to adolescents granting consent to become an organ donor. When the question to become an organ donor is unexpectedly asked when obtaining their driver's permits or license, teens have little time to consider all of the factors and ramifications that pertain to such a serious decision. More than likely, they give a spontaneous and impulsive response. It is important to remember that the decision to grant consent does not necessarily or always result in the actual behavior of donation, and unless one is consenting to be a living donor, the decision ultimately lies with the parent.

According to Simmons, Marine, and Simmons (1987), the decision-making process for living related donors has three criteria. First, is moral decision making, which represents spontaneous or unplanned choice making. Second, is deliberation, which is a conscious or mindful choice. Third, is postponement, where the potential donor delays making a decision and only becomes a donor based on everyone else being ruled out for various reasons. In this situation, the donor takes the position of not having to make a decision until there are no other options or possible donors; however, this still indicates a decision. Janis and Mann (1977) agree that there is a clear process through which one goes when considering becoming a living donor.



The process of decision making for next-of-kin, which happens when their loved one is pronounced brain dead, is a completely different situation and one filled with high emotions. Timing of the request and the person making the request may be taken into consideration in these cases (West & Burr, 2002). Because of this, it is important that family members are aware of their loved one's wishes. In some cases, the decision-making process may be simplified for next-of-kin by simply knowing what those wishes are.

### **Purpose of Study**

The purpose of this study was to gain insight on the perception that adolescents had regarding organ donation and the factors that contributed to their willingness to grant consent to become an organ donor. Because research on teenage organ donation has been done in metropolitan areas (Spigner, Weaver, Cardenas, & Allen, 2002), this research examined teenagers from a rural area. This research was important because there are thousands of people waiting for organs, and lives are being lost every day due to a limited supply.

The research would contribute to the literature regarding teenage perspectives and opinions about organ donation. With organ donation becoming more and more of a societal issue, the hope was to increase awareness of organ donation, which, in return, would increase the number of potential donors. Actual donors impact the number of lives saved each year and decrease the number of individuals on the waiting list. With thousands of teenagers receiving driver's licenses and permits each year, this is a targeted population for seeking consent for donation and a population who should be exposed to and made aware of the topic.

This study was a quasi-experimental design using a non-equivalent experimental and a control group consisting of approximately 40 students per group. The research consisted of a pre-survey and post-survey questionnaire with the experimental group receiving the treatment, which consisted of a curriculum (organ donation information, video, discussion of scenarios).

## **Research Questions**

The overarching research question that was examined was:

Q1: What factors do teenagers consider when making a decision to be willing to consent to become an organ donor at the time they receive their driver's permit or license for the first time?

This study examined the following variables: sources of information regarding organ donation; basic demographic information such as age, gender, ethnicity, religion, and parent's level of education; knowledge about organ donation; and willingness regarding organ donation. Based on these variables, other research questions included:

Q2: From what sources (family, school, media, etc.) do teenagers obtain knowledge about organ donation?

Q3: Does knowing someone (donor/recipient) increase willingness to consent to organ donation?

Q4: Are there significant differences regarding gender (male/female), ethnicity (white, Hispanic, etc.), and religion (Catholic, Jewish, etc.) among teenagers regarding willingness to consent to organ donation?

Q5: Is there a difference in grade point average between students who are willing to consent to organ donation and those who are not?

Q6: Is there a difference in knowledge between the experimental and control group (difference in score) regarding willingness to consent to organ donation?

Q7: What is the relationship between knowledge level and willingness to consent?

Q8: What is the relationship between knowledge level and perceived consent to organ donation?

The data that were gathered allowed for these questions to be answered.

## **Researcher's Perspective**

The perspective of this researcher is that teenagers often do not fully understand what they are being asked or the many factors that come into play when asked if they want to consent

to become an organ donor at the time they receive their driver's license or permit. Most people do not really think about organ donation and find it abstract or far removed from their daily lives, until they or a loved one is faced with a life-and-death situation. Although getting consent to become a donor from teenagers is important, because of their minor status, parents are ultimately the ones granting consent; perhaps it is more important to find ways to increase parental consent. With little research being done on individuals under the age of 18, this research will hopefully broaden the field of organ donation regarding teenagers and the factors related to their willingness to consent to become an organ donor.

I have witnessed two differing experiences with the Department of Motor Vehicle office. Four years ago when my daughter received her drivers' permit, DMV personnel asked her directly if she wanted to give consent to be an organ donor, while my most recent experience (April, 2013) with the DMV was to have the worker ask me, the parent, if I wanted my son to be a donor. My guess is that I was asked because parents have the final authority to grant consent when individuals are under the age of 18. The worker stated "that "if we had not talked about it before, we could take a few minutes at that time to do so." My first thought was "taking a few minutes" in a public setting with numerous people in line behind us is not the most conducive setting in which to be making such a serious decision. Because organ donation is such a highly emotional topic, it is important for teenagers to discuss their wishes with their parents or guardians.

### **Delimitations**

Those surveyed in this study included 9<sup>th</sup> through 12<sup>th</sup> grade students who attended a Weld County high school in a rural community in northern Colorado. The high school had an enrollment of approximately 840 students. The timeframe for the survey and data collection was

January-March, 2015. Many of these students had not yet obtained their driver's permits or licenses.

It is important to note that this was a study regarding willingness to consent to solid organ donation; willingness to consent to other types of donations, such as blood and plasma, were not addressed. Another delimitation is that the statements pertain only to solid organ transplantation and donation.

### **Assumptions**

The assumptions were that the participants in this study answered the survey questions thoughtfully, openly, and honestly and that the study generated discussions between the participants and their families. Another assumption was that the pre- and post-surveys were easily understood, and the experimental group would be more willing to consent to being organ donors, and the treatment (curriculum) about organ donation influenced their decision to consent.

## CHAPTER 2

### LITERATURE REVIEW

The history of organ transplantation began in the 18<sup>th</sup> century when researchers began experimenting on humans and animals. Over the years, scientists have continued to research and perform transplantation. By the 20<sup>th</sup> century, the first successful transplantation had been performed (cornea) (*Organ Donor History*, n.d.), and in 1954, the first successful living-related kidney transplant was performed on identical male twins in Boston (Merrill, Murray, Harrison, & Guild, 1956). Table 1 displays a truncated timeline of the history of organ donation. The most commonly transplanted organs are kidneys, livers, hearts, and lungs (Nilsson, Persson, & Forsberg, 2008). With advancements in the medical field, physicians now perform hand and facial transplantations (*Organ Donor History*, n.d.).

Until 1980, successful organ transplants were rare even with the advancements in technology 10 years earlier. Transplants became more successful due to the immunosuppressive medications. These medications, cyclosporine and other drugs, decreased the chances of one's body rejecting a newly obtained organ and increased successful transplants around the country. In 2014, there were approximately 14,000 transplanted organs nationally, consisting mainly of pancreas (114), lungs (929), hearts (1,244), and livers (3,287), with the majority being kidneys (8,324) (OPTN, 2014). The number of transplants doubled from 1988 to 2004 (Healy, 2006); however, in the last 10 years, there has been little change, with total donors being 14,154 in 2004 and increasing to 14,412 in 2014 (Carey & Gonzalez, 2015). Since 1988, almost 400,000 organs have been transplanted (IOM, 2006).

Table 1

*Organ Donation/Transplant Events from the 1860s to the Present by Decade (Appendix C)*

Decade	Organ Donation/Transplantation Event(s)
1860s	First skin transplant
1900s	First cornea transplant
1950s	First successful kidney transplant (identical twins) First successful kidney transplant (fraternal twins)
1960s	First organs recovered from a deceased donor First organs recovered from a brain dead donor First United States heart transplant First organ procurement organization established
1970s	Discovery of cyclosporine
1980s	First combined lung/heart/liver transplant First successful intestine transplant First split-liver transplant National Organ and Tissue Donor Awareness Week declared by Congress (4 <sup>th</sup> week of April)
1990s	First successful living lung transplant Nobel Prize (in physiology or medicine) awarded to Dr. Murray and Dr. Donnall Thomas First hand transplant in the United States Organ Donor Act was passed by Congress
2000s	Number of living donors exceeds number of deceased donors; first partial face transplant in France Human Health Secretary designates April as National Donate Life month Campaign launched by the National Kidney Foundation to eliminate the kidney wait list

## **Policy**

Researchers believe that social problems do not exist per se, but are constructed. There are three factors that come into play when constructing a social problem: (a) choosing the problem; (b) defining the problem; and (c) offering an explanation of the problem (Blau & Abramovitz, 2007). One issue is who gets to decide what constitutes a social problem. More often than not, it is those who have political power or leaders who are in the media. Another issue with policy is that the individuals who make the policy are often far removed from the very people the policy is to benefit or meant to help.

Each individual has their own perspective of how policy should be implemented. Sometimes people have a personal experience that motivates them to lobby for bills and policies to be passed or defeated. Because of this, there are various factors that come into play regarding one's decision making (e.g., political view, culture, or background). Due to this, policies can often be limiting for the specific individuals who are supposed to benefit. Social policy can be seen as an attempt to rectify the problem. Karger and Stoesz (2010) define policy as a systematic model for analyzing a specific social welfare policy or series of policies. In regards to policy, it is important to keep in mind that it is ever changing.

Policy surrounds us in all aspects of our daily life from education, transportation, health care, and what we eat. Very seldom do we stop to think about the policies that impact us on a regular basis. Although the current and/or proposed policies regarding organ donation can be controversial to many, it is important to analyze and ponder why such policies are currently in place and/or why some want to see change. For example, as a result of policy change, responsibility for donation requests were altered from medical professionals to organ procurement coordinators in the mid-1990s (Anker & Feeley, 2011).

## **Organ Donation Policies**

Important legislation regarding organ donation consists of The Uniform Anatomical Gift Act (1968, 1987, and 2006), The National Organ Transplant Act (1984), and The Patient Self Determination Act of 1991 (“Organ Donation”: Encyclopedia of Everyday Law, n.d.). These policies have the patient’s welfare in mind.

**Uniform Anatomical Gift Act.** The Uniform Anatomical Gift Act (UAGA) makes sure the process of organ donation is done in an ethical manner. It gives the next-of-kin the right to make decisions regarding a person’s decision to provide an organ donation; the Act was to originally reduce health care professional liability (Uniform Anatomical Gift Act, 2010). It allows for the wishes of the donor to be carried out. With this Act, if a donor has given consent, the family has no right to revoke the wishes of the deceased. However, the required request legislation, which requires all hospitals to discuss the option of donation with potential donors and their families (The Omnibus Budget Reconciliation Act of 1986), has received scrutiny due to the fact that it poses an ethical dilemma for medical professionals. Within a short timeframe, it mandates a physician to view a patient as a potential donor, thus changing the course of treatment. In some cases, treatment to keep the patient alive is in direct conflict with treatment to maintain viable organs. While UAGA intended the patient care team to be distinctly different than the transplant team, the required request legislation removes the distinction and makes them one in the same. Families are confronted with a psychological experience in that they are trying to comprehend a diagnosis of brain death as they view their loved one having a pulse and breathing. Some believe this is the next step for presumed consent (Martyn, Wright, & Clark, 1989). Although there is legislation in place, kin ultimately have the choice, and medical professionals will more than likely follow the family’s wishes.



**National Organ Transplant Act.** In 1984, the National Organ Transplant Act (NOTA) began to offer structured guidelines acknowledging the medical advancements regarding organ donation. At that time, kidney transplants had an 80% survival rate, and immunosuppressive drugs such as cyclosporine had increased the survival rate for liver recipients from 35% to 70% the first year after the transplant. NOTA provides resources for grants for eligible organ procurement organizations (OPOs) and the Organ Procurement and Transplantation Network (OPTN). The OPTN was intended to assist OPOs in appropriately distributing organs that could not be used in the OPO's specific geographical region and to maintain a national registry for organ matching (*Organ Donation: Encyclopedia of Everyday Law*, n.d.).

**Patient Self Determination Act.** The Patient Self Determination Act (1991) was established to inform patients of their rights regarding their medical care. Included were the right to (a) facilitate their own health care decisions, (b) accept or refuse medical treatment, and (c) make an advance health care directive ("*Organ Donation: Encyclopedia of Everyday Law*," n.d.).

The Revised Uniform Anatomical Gift Act supersedes all state acts and poses challenges to the Patient Self Determination Act. For example if a patient entering the hospital states he/she does not want to remain on mechanic support, the possibility of procurement may be affected due to this choice and may take away the rights of the next-of-kin (Verheijde, Rady, & McGregor, 2007). Some may say that removing a patient from a mechanical support system is unethical, while others may see it as an option for dignity.

Current policy in the United States indicates donation is voluntary as one opts to grant consent to become a donor. Some believe that to increase donor rates and decrease the time on waiting lists, the United States should move to a presumed consent philosophy, which is what

many European countries (e.g., Spain and Sweden) have (Neades, 2009). With this policy, one is assumed to be a donor unless one opts out or declines to grant consent to become a donor.

Other current policy states children under the age of 12 are not eligible for adult lungs; however, with the publicity surrounding a 10-year-old girl in Pennsylvania, her parents and other advocates for organ donation are asking legislation to alter this regulation (The Denver Post, 2013). Although some are in favor of the changes in policy, others feel that transplantation of adult lungs into a child is risky and may not be successful, resulting in a waste of organs.

### **How to Become a Potential Donor**

There are two specific ways to identify as an organ donor. These consist of giving consent on one's driver's license and/or registering with an organ donor agency.

#### **Department of Motor Vehicle**

Because thousands of people each year receive their driver's permit and/or driver's license and many renew their licenses, it is much easier for people to grant consent to become a donor through the Department of Motor Vehicles (DMV) than through the registry. According to Sue from Donor Alliance (personal communication, July 11, 2013), most states provide both methods.

Although the DMV personnel ask if individuals want to become donors, and they have posters with contact information and pamphlets regarding donation, they do not directly give specific information about organ donation, recipients, or the waiting list to individuals when they are being asked to give consent. It is important to keep in mind that this was the procedure in one DMV office in Northern Colorado. In Colorado, the DMV is a partner with Donate Life Colorado.

According to A. Smith, owner of Mountain State Drivers Education (personal communication, May 9, 2012), when students take the six-week class and are preparing to receive their permit, they are shown a short video about organ donation, but do not engage in a discussion regarding the topic. He states, “Why should we. It is a personal choice.” Having discussions may be helpful for awareness, basic knowledge about organ donation, and communicating one’s wishes; as a result, these conversations may increase the number of donors.

### **Registries**

Every state has a donor registry or an agency one can access online to register. In the state of Colorado, the registry is Donate Life Colorado ([www.donatelifecolorado.org](http://www.donatelifecolorado.org)). Anyone of any age can be a donor, while those under the age of 18 need parental consent. There are many frequently asked questions regarding organ donation (Appendix D).

Registries ask basic demographic information such as name, date of birth, address, and limitations. Limitations refer to specific organs one does not want to donate. The registry allows one to change their mind and have their name removed from the registry, resulting in a non-registered status. To have one’s name removed from the registry, one can fill out the necessary forms online or mail a request. Although one may have a non-registered status, at the time of death, family members may be contacted to see if they would like to make a donation on behalf of the deceased.

### **Criteria to Be a Donor**

Anyone of any age can give consent to be an organ donor; however, parents of individuals under the age of 18 make the final decision for their children/youth. Individuals with health issues should not assume they cannot be potential donors. At the time of death, one’s

medical records are reviewed to assess relevant information, which may prevent one from being a donor. People who have had certain types of hepatitis and cancer can still be eligible to donate certain organs (Midwest Transplantation Network, 2013).

Once a donor is available, criteria considered for successful matching include age, blood type, size of organ (at times), level of urgency, times spent on the waitlist, and the distance between the donor and recipient. It is important to keep in mind that each organ has specific matching criteria (Petechuk, 2006).

Other things that are taken into consideration include whether the candidate has high antibody levels, which can be incompatible with a donor and can lead to rejection of an organ, and the current health of the candidate. In some cases, the perspective recipient is not healthy enough to receive the organ or undergo surgery. Physicians have one hour to accept or decline an organ once it becomes available (UNOS, 2013); clearly, time is of the essence for the recipient of the donation. Figure 1 displays the procedure from the time a patient enters the hospital to the time of the transplant. The procedure varies based on each state's policy, type of organ, and travel time of donor (Midwest Transplant Network, 2013).

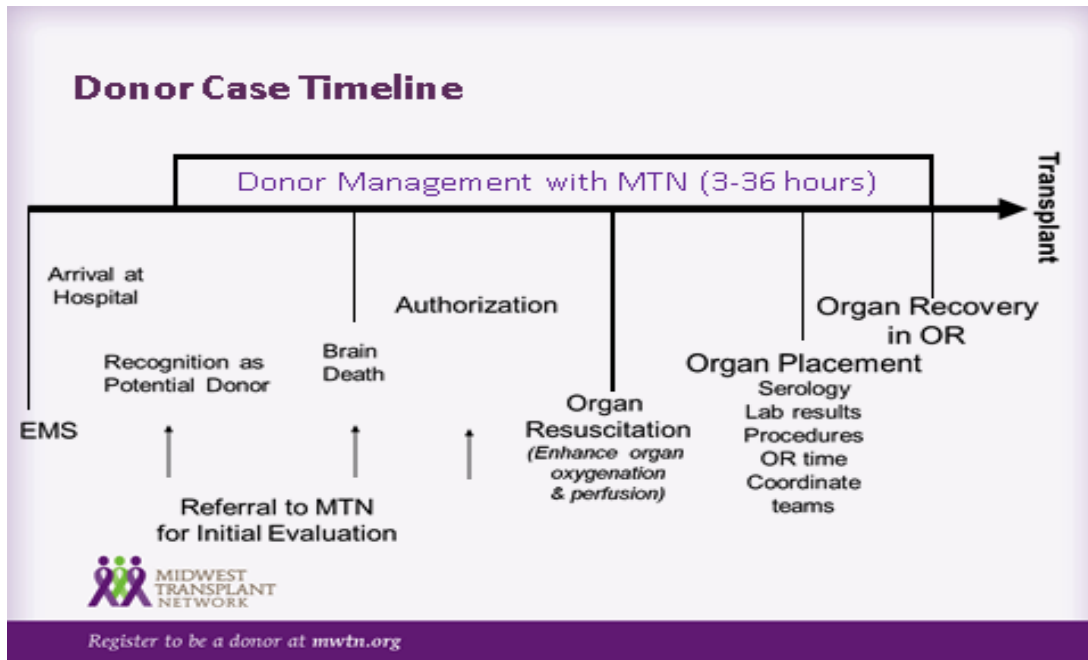


Figure 1. Donor case timeline.

### Factors in Becoming a Donor

The literature demonstrates that knowledge is a key factor in organ donation and is usually absent for most people. Thornton et al. (2006) report that teenagers, in general, have a lack of knowledge regarding organ donation. Research (Morgan & Miller, 2002) suggests that increased knowledge leads to a more positive attitude, which in turn, leads to higher rates of consent. However, little research has been done to assess knowledge about organ donation and teenagers as studies usually do not include individuals under the age of 18 (Spigner et al., 2002). One issue is where and how information about organ donation should be or could be disseminated.

### Hospitals

Local hospitals are where donors become available. Hospitals have firsthand knowledge of potential donors. It is the responsibility of hospital personnel to contact the local organ procurement organization (OPO) when a potential donor is identified. Personnel from the OPO

contact the next-of-kin. Several states have passed “routine notification” laws, which require that all deaths be reported to the local OPO (Healy, 2006). Most donated organs come from people who are declared brain dead (Caplan, 2008).

### **Medical Professionals**

According to medical personnel Joan Welsh (personal communication, June 17, 2011), when a situation occurs where an individual is on life support or is approaching expiration, hospital personnel will contact an organ procurement organization (OPO) to make contact with the family to attempt to get consent for donation. According to Caplan (1984), doctors and nurses did not want to inquire about organ donation due to the intense emotionality of the subject; it was uncomfortable for the medical professionals and the families. Physicians were put in a somewhat precarious situation when caring for patients and having to ask family members to grant consent. This led to some of the distrust by family members of the medical profession. Because of this, staff members from the local OPOs now approach the family only after they have been notified that their loved one has died (IOM, 2006). The OPO in Colorado is Donor Alliance, and as mentioned before, is responsible for increasing donors and facilitating donations.

### **Organ Procurement**

In some situations, personnel from the OPO are housed in hospitals (Healy, 2006). OPOs emphasize that for some, donation is a way to make sense of a tragic and unexpected death (Healy, 2006). Some of the OPOs have a required request philosophy. This philosophy implies that all OPO personnel will make a required request of a family for their loved one to be a potential donor, regardless if they have or have not indicated their wishes to donate through the DMV (drivers’ license) or a state registry (Healy, 2006).

At this time, the family or next-of-kin is asked to give consent for organs to be recovered and donated. Time is crucial, and many actions need to take place such as histocompatibility testing (matching), recovery the organs, and organizing transportation of the organ(s) to increase a timely and successful transplantation.

### **Request of Families**

A number of research projects have addressed the manner and method in which the family is asked about donating their loved one's organs (Bires, 1999; Nathan et al., 2003). They found a variety of circumstances come into play.

One study (DeJong et al., 1998) found that non-donor families were not satisfied with the quality of care their loved one received and felt like they did not have sufficient time or privacy to consider the possibility of donation. Burroughs, Hong, Kappel, and Freedman (1998) found that donor families report greater satisfaction with care compared to non-donor families. According to IOM (2006), specialized skills are needed from the requesters. One model (Zink, 2004) presents organ donation as the expectation and uses open-ended questions to steer the discussion. With this approach, there needs to be clear boundaries to present the opportunity for donation without duress. Zink (2004) reported there needs to be more research on this approach in regards to family response, donation rates, and ethics.

### **Timing**

Early research indicates that timing of the request to donate did not impact consent rates (Morris, Slaton, & Gibbs, 1989). The Institute of Medicine (2006) reports that early and consistent involvement with the family with an emphasis on effective communication increases donor rates, especially if there was an in-house coordinator. Other research on in-house coordinators has found similar results (Shafer et al., 2004).

## **Elements of Request**

In a collaborative learning session, the Health Resources and Services Administration (2005) identified elements of effective requests to be acknowledging the uniqueness of each family, providing compassion, and determining the most appropriate requester and timing in each case as families of patients may have built rapport or bonded with specific medical personnel. Other elements include questioning assumptions regarding cultural and ethnic differences; discussing organ donation as an opportunity for a recipient and as a possible healing for the donor family; and lastly, continuing to provide compassionate and excellent quality of care to the patient and the family regardless of the decision (Health Resources and Services Administration, 2005).

## **Grieving Process**

Research on the grieving process of donor families varies. Manuel, Solberg and MacDonald (2010) reported that donation can either facilitate or hinder the grieving process. Pelletier (1992) reported that donation can elicit a sense of comfort; however, Warren (2002) suggested there is a consensus from researchers that the thought of organ donation creates anxiety for the family and likely hinders the grieving process. According to Cleiren and Van Zoelen (2002) donation has no impact on the grieving process for family members.

## **United Network for Organ Sharing**

If the family gives consent, the next step is to find a person on the waiting list who is a good match. Recipients are put on the waiting list after they have been evaluated and deemed to be an appropriate candidate for transplantation. Each medical profile is sent to a national wait list registry, the United Network for Organ Sharing (UNOS). When an organ becomes available, the OPO sends information to UNOS to generate a list of potential recipients based on compatibility. Compatibility criteria include blood type and medical urgency. Once a recipient



is found, an organ specialist from either the OPO or UNOS contacts the transplant center (hospital) where local patients are high on the list (Petechuk, 2006). If a local or regional recipient is not found, UNOS continues to look outside the region to seek a potential recipient. The United States is divided into 11 geographic regions. Colorado is in a region that includes Iowa, Kansas, Missouri, Nebraska, and Wyoming (Healy, 2006). Once a recipient is identified, the recipient is contacted and must immediately go to the transplant center to prepare for the process of transplantation.

### **Criteria to Be a Recipient**

An individual initially needs to get a referral from their doctor to be put on the United Network for Organ Sharing national waitlist. The next step is to contact a transplant center (hospital) that will be appropriate for one's needs. Individuals then meet with medical professionals to evaluate their situations and needs and review medical records. Once a perspective recipient meets with medical professional to evaluate his/her status, the transplant team will determine whether one is an appropriate candidate to receive an organ. Within 10 days, one will be notified by the transplant center if their name will be added to the waiting list (UNOS, 2013).

Other things taken into consideration include whether the candidate has high antibody levels, which can be incompatible with a donor and can lead to rejection of an organ, and the current health of the candidate. In some cases, the perspective recipient is not healthy enough to receive an organ or undergo surgery (UNOS, 2013).

### **Organizations' Perspective and Roles**

The field of organ donation has many organizations and governing bodies ranging from united networks to local facilities, all working within their roles and regulations. Many of the facilities have numerous individuals working toward a successful donation.

## **United Network for Organ Sharing**

In 1984, the United Network for Organ Sharing (UNOS), a non-profit and private organization, was developed; the network oversees the organ donation system. This system has been evolving since being formed by federal and state laws (IOM, 2006). Within this system are the Organ Procurement and Transplant Network, (OPTN), Organ Procurement Organizations, (OPO), transplant centers, histocompatibility laboratories, and health organizations. A goal of UNOS is to establish a national system to ensure that candidates have an equal chance to obtain a needed organ. To help make this possible, a database was developed to compile information and medical records for individuals on the waiting list. This is done through the OPTN. When an organ becomes available, UNOS generates a list of potential recipients (Petechuk, 2006).

The OPTN consists of 58 organ procurement organizations (OPOs) throughout the country, considered to be the “donate life organizations,” for each state. Their goal is to develop policies and implement an equitable system. They are responsible for solid organ donation and transplantation regarding deceased donors and have little responsibility in regards to living donations. OPOs and transplant centers are mandated to participate in the OPTN (IOM, 2006).

Fifty of the OPOs are independent, while eight are hospital or university based; each organization serves a specific geographical area. In each region, from 1 to 17 million people are served; the number of facilities varies from 12 to 220 hospitals in a single area (IOM, 2006). The number of referrals and organs procured also varies. For example, in 2003, the referrals ranged from 52 to 2,627, while the number of organs recovered in each region ranged from 86 to 1,181. Based on these numbers, one can see how one OPO may differ compared to other OPOs. The OPO is responsible for educating the public, improving donation rates, and recovering tissue and solid organs; they work with individuals, families, and hospitals to gain consent and

facilitate organ donation. They have the capacity to recover, store, and deliver organs (Healy, 2006). In Colorado, the OPO is Donor Alliance located in Denver.

Transplant centers are hospitals that perform transplants. In 2005, there were 267 transplant centers operating approximately 860 transplant programs in the United States (UNOS, 2005). It is important to know that not all transplant centers transplant all organs. Some centers perform transplants on specific organs (UNOS, 2013). For example, in Colorado there are four transplant centers, and two perform heart transplants (Appendix E).

The centers have teams consisting of a transplant coordinator who is generally a registered nurse and the main contact person for the candidate and the rest of the team. The team is coordinated for one's care. The surgeon evaluates the current status, makes recommendations, and eventually performs the surgery. The physician, a specialist in nephrology (kidney) or cardiology (heart), helps assist in evaluation and care. The financial coordinator assists the candidate on financial matters for the cost of a transplant. An insurance case manager provides knowledge about insurance coverage; social workers assist the recipient and/or family with resources such as support groups and psychosocial issues that may arise; a dietician develops a nutrition plan before and after the transplantation occurs.

Histocompatibility labs do the testing to determine if a potential recipient will be a good match to receive an organ. The testing is based on the human leukocyte antigen (HLA) matching criteria; blood, tissue, and sometimes genetic testing are done. In 2006, there were 59 independent labs throughout the country (Healy, 2006).

## **Societal Factors--Media**

The topic of organ donation is often depicted in the media (Feeley & Vincent, 2007; Harrison, Morgan, & Chewning, 2008). However, it is not always depicted accurately or positively (Maloney & Walker, 2000; Morgan, Harrison, Chewning, Di Corcia, & Davis, 2007).

Even people in the public eye are in the media; in a Denver Post article (June, 17, 2013), former Vice President Dick Cheney briefly mentions he has had five heart attacks leading to a battery-operated heart pump and, ultimately, a heart transplant in 2012 at the age of 71. Organ donation has been seen in the media in several instances for decades. In the 1980s, there was baby Fae who received a baboon heart (Petechuk, 2006). In 1994, when Nicholas Green was shot on a family vacation in Italy and his parents donated organs, the case provoked much sympathy (Healy, 2006). More recently, there has been much focus by the media on a 10-year-old girl in Pennsylvania who is in need of a lung. In this situation not only is the topic of organ donation itself the focus, but policies and possible change of policies is addressed (Szabo, 2013).

In a pilot study, Maria Banevicius (1992) found that donor families would like to have some sort of follow-up to see how the recipients are doing, whether it is a meeting or correspondence. In recent research, Shaw (2011) found it was the absence of discussion between the donor family and the recipient that was problematic. Perhaps donor rates would increase if donor families could have some sort of contact with the recipients. Banevicius' study found that, at times, a donor family was somewhat disappointed after finding that the heart of their 19-year-old daughter was now beating inside a middle-aged man.

Stories of donor families meeting recipients are rare, but are publicized on occasion. In 1993, when six people were killed in the Long Island railroad shooting, the parents of Amy Federici donated her heart, liver, and kidneys. *People* magazine traced the recipients, and Amy's

parents were able to meet them. Amy's father, Jack Locicero, stated they have family-like ties, especially with the heart recipient, a woman named Arlene. Stories surrounding tragedy are in the media, and they often report how recipients meet the donor family, but the actual occurrence is very rare in daily practice. Usually, the only information donor families receive is the age, gender, and general location of the recipient (Healy, 2006).

In other cases, people have chosen to use other forms of media to seek organs. In 2004, a 32-year-old man suffering from liver cancer advertised for an organ on billboards on Houston, Texas, highways; although he did receive an organ, he passed away eight months after the transplant (Petechuk, 2006). Some have gone as far as using social media and paying a monthly fee in an attempt to access organs online. According to Petechuk (2006), a doctor in Denver solicited a kidney donor from MatchingDonors.com for a monthly membership of \$295.

Robert Smitty became the first web site donor on October 20, 2004, at Presbyterian/St. Luke's Medical Center in Denver, Colorado, where the transplantation was conducted (Davis, 2004). Although it would be unethical, this leads one to speculate if individuals may try to advertise or access organs on Craig's List.

With movies like *My Sister's Keeper* (2009) and *Seven Pounds* (2008), it is clear to see how the topic of organ donation can become controversial and how there are many aspects to be taken into consideration. On occasion, one hears public service announcements on the radio briefly stating the benefits of organ donation and the number of individuals who can be helped. The few public service announcements name Donor Alliance as the contact and were heard on a local radio station.

Because organ donation is an emotional topic and often deals with life-and-death circumstances, it could be considered responsible and in the best interest of the media to portray

this topic accurately to increase awareness and benefit the general public. With the amount of time the general public spends watching television, reading newspapers, and accessing the Internet for information, it would serve the public well to hear correct reports.

### **Myths**

The media, specifically television and movies, often portrays myths about organ donation and allocation (Morgan et al., 2005). Many myths are negative, and negative portrayals have been shown to lead to a decrease in consent. In one study, 15 months after a prime time television program which highlighted death criteria in the United Kingdom, decreases in consent were still being seen (Bradley & Brooman, 1980).

Several myths surround the topic of organ donation; for example, some individuals believe that if the medical staff knows one is a donor, doctors may be less likely to try to save one's life and remove organs before one is truly dead (Arriola, Perryman, & Doldren, 2005;Haustein& Sellers, 2004). This mistrust leads some to believe in unjust allocations of organs and that the wealthy and/or famous are more likely to receive a transplant (Haustein & Sellers, 2004; Morgan, Harrison, Afifi, Long, & Stephenson, 2008) and organs being given to undesirable recipients who are considered to be responsible for their own illness (Haustein & Sellers, 2004). It is ideas like these that keep people from donating needed organs (Morgan et al., 2007). Another myth is the idea of a black market.

### **Black Market**

Morgan and Miller (2002) found that from 59-75% of Americans believe that a black market exists for organs and, according to medical personnel J. Welsh (personal communication, June 17, 2011); it does—outside the United States. With even one of the myths being

legitimized, it makes people wonder if there is some truth to other myths or concerns regarding organ donation.

In 1984, the National Organ Transplant Act was introduced. Although this Act makes it illegal to acquire, receive, or transfer any human organ, other countries continue to participate in such actions. In December of 2003, leaders in an international ring of kidney trafficking were captured; and a town in India is known as the “kidney village” due to the many people who have illegally sold one of their kidneys (Petechuk, 2006, p 84). Like the United States, other countries (Turkey, Brazil, Israel, Argentina, and Russia) have laws against the buying and selling of organs, but they neglect to enforce laws prohibiting the sale of organs (Petechuk, 2006).

In 2002, a millionaire from London bought a kidney from a Pakistan girl; although he was on a waiting list, he was becoming concerned that he would die before he received the needed organ. In China, officials have admitted to selling prisoners’ organs to foreign recipients (Petechuk, 2006). In the United States, with the many organizations, policies, and regulations in place, it would be difficult for a black market to exist; however, outside the country, it does. Unfortunately, organ donation is not exempt from corruption.

### **Personal Factors Contributing to Consent**

Three key concepts related to consent are attitude, knowledge, and communicating one’s wishes (Sirois, Sears, & Marhefka, 2005). Individuals have their own values, beliefs, and attitudes that guide them in all areas of life.

#### **Attitude**

In general, surveys on attitudes regarding organ donation reveal more than half of the general populace has an optimistic attitude when considering donating their organs. A large

portion of the population is undecided, with the smallest group having a negative attitude (Barcellos, Araujo, & Da Costa, 2005).

### **Knowledge**

One main problem to which the literature consistently refers is the lack of knowledge that most individuals have regarding organ donation. Knowledge can be defined as basic information about organ donation. The fortunate thing about knowledge is that it can be easily targeted through driver's education courses, the DMV, or school curriculum.

According to Rubens (1996), strong correlates for signing an organ donation card for White undergraduate students ( $n = 683$ ) were support for donation, knowing someone who signed a donor card, knowing someone who was a recipient of a donor, and knowledge of the organ donation system. Most knowledge that college students have about organ donation comes from the media followed by interpersonal relationships (Feeley & Servoss, 2005). Research suggests there is virtually no manner in which the general public gets direct information regarding organ donation other than the media,-specifically, television (Morgan, King, Smith, & Ivic, 2010).

### **Communicating Wishes**

Although one may sign a donor card or drivers' license indicating their consent to become a donor, in many situations the donor does not communicate or discuss their wishes with their loved ones or next-of- kin (Radecki Breitkopf, 2006). Because of this, next-of-kin may not know about or be prepared to carry out the wishes of the deceased.

The Uniform Anatomical Gift Act provides that the process of organ donation is done in an ethical manner. With this Act, if a donor has given consent and specified an anatomical gift, the family has no right to revoke the wishes of the deceased. However, if the next-of-kin does



not agree with the wishes of the deceased to become an organ donor, medical professionals will most likely respect the family's wishes. It gives the next-of-kin the right to make decisions when there is an absence of documentation regarding organ donation; the Act reduces health care professionals' liability and allows for the wishes of the donor to be carried out (Uniform Anatomical Gift Act, 2010).

### **Additional Factors Contributing to Consent**

It is important to keep in mind that because an individual gave consent to be a donor does not mean that their wishes will be granted. In daily practice, even in situations where individuals have indicated a desire to donate, the family is still asked. Hospital, medical, and OPO staff generally defer to the wishes of the next-of-kin, for they are the actual donors (Healy, 2006). If the family or next-of-kin does not give consent, the organs will not be recovered, and transplantation will not occur.

The hierarchy of priority includes spouse, parents, and kin. If next-of-kin are available, carrying a donor card is not sufficient for recovering organs. Other research has found differing approaches (Wendler & Dickert, 2001). After a complete exploration of the family, if no family members exist, a medical examiner decides whether the individual can be a donor.

The next-of-kin will ultimately have to grant approval, and family consent is crucial regarding organ donation. It is at this time when many people say no to organ donation. A family's refusal to donate has been the main reason for the loss of potential organs (Weiss, 1996), and refusal rates can be as high as 80% for next-of-kin (Barber, Falvey, Hamilton, Collett, & Rudge, 2006).

One reason why family members refuse donation is because they have difficult time processing information about the death of a loved one while being confronted with the request for an organ donation (Long, Sque, & Payne, 2006). At this point, the abstract concept becomes reality, and grieving families may be too overwhelmed with this decision. At times, when the family is so distressed, the topic of organ donation was not approached (Cleiren & Van Zoelen, 2002; Neades, 2009).

There are other personal factors that come into play regarding consent. For example, age and gender (Pierini et al., 2009), ethnicity and/or culture (Park, Smith, & Yun, 2009), religion (Morgan et al., 2005), and level of education (Conesa et al., 2003), all are very important factors that have been studied regarding organ donation consent.

### **Age**

About 75-85% of teenagers are interested and possibly willing to become donors, but like adults, approximately one-fourth have actually given consent (Pierini et al., 2009; Radecki & Jaccard, 1997). Although teenagers may initially grant consent, individuals under the age of 18 must have parent approval for donation and transplantation to take place.

In a study of living kidney donors, many people feel that it is more socially acceptable for an older individual to donate organs to a younger person as opposed to a younger person donating to someone who is older, mainly for fear of long-term donor health problems (Piccoli et al., 2004). Based on the current research, teenagers and adults appear to have similarities regarding willingness to consent.

### **Gender**

Men are less likely to donate and less likely to have discussions about organ donation (Thompson, Robinson, & Kenny, 2003). Other researchers (Thornton et al., 2006) found teenage girls were more likely to have discussed their intentions to donate with family members

compared to boys. Female Hispanics were found more likely to donate than their male counterparts (Alvaro, Jones, Robles, & Siegel, 2005).

Wells (2005) found similar results indicating women having a higher willingness to donate compared to males. Other studies found gender was not a factor regarding willingness to consent (Boulware, Ratner, Cooper, Sosa, LaVeist, & Powe, 2002; Haustein & Sellers, 2004).

### **Ethnicity**

Studies have shown that ethnicity plays a role in granting consent (McNamara, et al., 1999; Park et al., 2009; Rubens, 1996). Cheung, Alden, and Wheeler (1998) and Lam and McCullough (2000) indicated that specific barriers are unique to specific minority groups.

African Americans have distrust for health care professions when it comes to saving lives. They believe that doctors will not work as hard to save their lives (Siminoff & Saunders Sturm, 2000). Rubens (1996) found that African-Americans were the least supportive of organ donation. Other researchers (Spigner et al., 2002) uncovered similar findings, and Rubens (1996) reported that there was a significant difference between African-American college students compared to White students in their attitudes and beliefs toward organ donation. For example, Whites in general supported organ donation (89.5%), while a smaller percentage of African Americans supported donation (61.8%). Whites thought it important to communicate their wishes regarding organ donation at 75%, while the percentage of African Americans put less importance on discussion at 60.8%. Another difference was that Whites felt it was appropriate to offer an option request on one's drivers' license at 84.5%, while African Americans responded with 59.7% regarding an option request.

Hispanic Americans were found to have lower rates of donation due to language barriers and the importance of family discussions (Rene, Viera, Daniels, & Santos, 1994). Other research

found that adult Hispanics have positive attitudes about living kidney donation (Siegel, Alvaro, & Hohman, 2011).

Consent to donate was more an issue of lack of knowledge than one of a racial or cultural difference. Researchers indicate that minorities have less access to medical care and information regarding organ donation (Yuen et al., 1998). Although minorities may be less likely to grant consent, approximately 52% of the people waiting for transplants are minorities (Park et al., 2009).

### **Religion**

None of the major religions prevent organ donation (Appendix F); however, personal views may hinder consent. Woo (1992) and Wheeler, O’Friel, and Cheung (1994) have suggested that religion and spirituality can be a barrier to granting consent, and beliefs may include the idea of the body remaining whole and not disturbing the death process. For example, one may believe that you cannot reach the afterlife if you are not physically whole. Rubens (1996) reports religion as a barrier to organ donation. For example, Buddhists believe the dying process lasts 49 days after an official declaration of death (McGregor, Verheijde, & Rady, 2008). A devout Hispanic Catholic may feel that donating their organs may influence their chances of eternal life (Chapa, 1992). Later research by Pierini et al., (2009) found no differences regarding teenagers who were Catholic and atheists and their willingness to consent.

### **Level of Education**

Level of education may be a factor regarding willingness to consent. It has been suggested that the more education one has, the more willing one is to grant consent (Conesa et al., 2003). Gallup (2005) and Radecki and Jaccard (1997) reported similar findings with adults,

indicating individuals with bachelors and graduate degrees had higher levels of intention and more positive attitudes regarding the likelihood to donate.

## **Risks**

Literature documents pro-social reasons why individuals should consider becoming an organ donor. Like any surgery, transplantations have risks, such as complications, infection, and death. However, there is little information regarding the risks of transplantation. Individuals need to take into consideration the risk-benefit and decide whether the benefit outweighs the risk (IOM, 2006). This is basically the analysis or assessment of the pros and cons regarding organ donation. This assessment may be subjective; what one views as a risk may not be viewed by someone else as a risk.

Early in treatment history, over half of the 64 kidney donors reported mild to severe trauma up to six years after the transplant (Hirvas, Enckell, Kuhlback, & Pasternack, 1976). Other researchers indicate that donors have a psychological risk when the recipient is a family member and the organ is rejected or death occurs (Weizer, Weizman, Shapira, Yussim, & Munitz, 1989).

In regard to living-related donation, Aujoulat, Schwering, and Reding (2011) reported two cases where a child and a teenager felt so indebted and obliged to their parents for the donation that, even as young adults, they were struggling with their “mental well-being.” They also reported one teenager who chose to be transplanted by a deceased donor even though both of his parents were willing to give the needed organ. He felt by receiving one of his parent’s organs, that he would be too indebted to them.

## Efforts to Increase Donor Consent

With the constant need for organs and the long waitlists, organ donor proponents have suggested various ways to increase the number of donors. These include presumed consent, incentives, and education.

### Presumed Consent

Many European countries have presumed consent or “opt-out” preference (Verheijde, Rady, McGregor, & Friederich-Murray, 2009). With this option, individuals are assumed to be donors, unless they specify that they do not agree with donation. When an individual chooses to “opt-out,” they are saying no to donation. Currently, all 50 states in the United States have the philosophy of an “opt-in” preference. Based on this option, individuals wanting to become donors say yes to consent.

In January of 2011 in Colorado, policy makers introduced the opt-out default option (*Organ Donor Bill stirs controversy*, 2011). States such as Illinois, Delaware, and New York have attempted to pass the presumed-consent approach; however, many people feel that individual choice will be taken away and the process is too intrusive (*Bill Would Make Coloradans Organ Donors by Default*, 2011). One Colorado politician stated that the change would simply make it easier for people who are already willing to donate. If Colorado were to go to “opt-out,” the Department of Motor Vehicle applicants would see a new statement that reads, “You are automatically deemed to have consented to being an organ and tissue donor, and this designation will appear on your driver’s license or identification card.” (*Bill Would Make Coloradans Organ Donors by Default*, 2011, p. 2). In 2010, New York failed to pass the presumed consent approach (*Bill Would Make Coloradans Organ Donors by Default*, 2011). Within a week of introducing the concept of presumed consent in Colorado, supporters said they

would drop the proposal. Although politicians were trying to make Colorado the first presumed consent state; reports indicate this was received with fear and opposition (“*Colorado Organ Donor Legislation Pulled*,” 2011). With all the policy and regulations surrounding organ donation, it is unclear as to how they came to this determination in such a short period of time. Regardless of informed or presumed consent, one still has a choice in becoming an organ donor.

There are two main kinds of presumed consent laws. “*Strong*” presumed consent laws rely solely on the individual to declare himself or herself a non-donor. With this situation, one still has a choice. “*Weak*” presumed consent laws allow for the family members of a decedent to opt-out if they desire to do so. With this scenario, one may feel that their choice has been taken away and left to next-of-kin. Kennedy et al. (1998) reported that in Austria, organs can be recovered from an individual despite the objection of next-of-kin; this approach is considered to be strong presumed consent legislation. Spain has a weak presumed consent law, where health care professionals always approach the surviving family members, not to request authorization to procure organs, but to see if they would prefer not to allow procurement to continue as it normally would (Presidential Council on Bioethics, 2006).

## **Incentives**

There are some who believe that the number of organ donors would increase if people were given some form of an incentive (Bruzzone, 2010). According to IOM (2006), this could be a financial or nonfinancial incentive. The financial incentive could go to the donor before death or to family members after death. An example of a direct financial incentive is a cash payment; an indirect financial incentive could be a reduction in health insurance premiums or college education benefits for children. A nonfinancial incentive could be some type of recognition or eligibility for a future transplant if needed. In Colorado, Senate Bill 167 authorizes

state employees to access seven days of paid leave for being a bone marrow donor and 30 days of paid leave for being an organ donor (National Conference of State Legislatures, 2013).

Currently, it is illegal to buy or sell organs; however, some feel that it would be appropriate for individuals to receive some type of incentive (IOM, 2006). Many economists believe that a market is almost always the best way to distribute a limited resource, and by doing this, there could be an efficient and reasonable way to increase the numbers of available organs (IOM, 2006).

Because poor people need money more than rich people, some believe the underprivileged would be taken advantage of. With concerns like this and others, the Institute of Medicine believes that a fair and appropriate functioning market is not probable (IOM, 2006). The more important question is--Would incentives actually increase donor rates? According to Kaserman and Barnett (2002), there is no actual evidence to say whether it would or would not; however, research may be able to address this question.

Some advocates state that individuals like payment, even if it is very minimal (Harrison & Alcorn, 2001; Kaserman, 2002; Tabarrok, 2009). It promotes the ability to access goods and services, so why would it not promote organ donation?

Much of society believes that human dignity should remain intact during life and at the time of death, and if organs are bought and sold, they will be thought of as a commodity, and human dignity may be pushed aside; this raises various ethical issues (IOM, 2006). Some researchers believe that the number of lives that may be saved outweigh these concerns (Barnett, Blair, & Kaserman, 1992).



## **Education**

Education programs are crucial to increase the number of donors (Weaver, Spigner, Pineda, Rabun & Allen, 2000) and may be the most convenient way to reach the adolescent population. According to Spigner et al., (2002), a high school health curriculum may be the most effective manner to disseminate information. Other researchers agree that direct classroom exposure and discussions may be effective to increase knowledge and inform this target population (Pierini et al., 2009; Thornton, Wong, Spigner, & Allen, 2010). School personnel along with educational administrators need to be on board with this approach. With lack of knowledge and little discussion with family members, teenagers are a growing population who can be targeted regarding organ donation. However, this group often has little exposure to knowledge regarding organ donation.

Due to the timing of teenagers receiving their driver's permits and/or licenses, it would seem to be an opportunity for school personnel to access this captive audience. Implementing classroom education for high school students is essential for increasing exposure and knowledge which, in return, may lead to an increase in the number of donors. Thompson, Knudson and Scully (1997) found that classroom discussions often led to students having conversations with their parents. Some researchers feel that a website curriculum could be an efficient method to educate teenagers, assuming one had access to a computer (Vinokur, Merion, Couper, Jones, & Dong, 2006).

Regardless of the educational curriculum method, the ultimate goal of education is to increase awareness, which will hopefully lead to an increase in donors. With the constant and growing need for viable organs and teenagers being in a high-risk age group for car accidents, school-based education is a societal need.

## **CHAPTER 3**

### **METHODOLOGY**

In this chapter the organization consists of the introduction, research questions, pilot study, instrument, research design, and data collection and analysis. The purpose of this study was to examine the factors that influence teenagers when they are considering granting consent to become an organ donor.

The nature of this research was quantitative pre/post intervention and was considered to be quasi-experimental due to a lack of randomization. There were numerous independent variables (predictors) and one dependent variable (outcome). The experimental group received the treatment (curriculum), and the control group did not. The research questions pertained to associational, comparative, and descriptive questionings.

A Gallup poll (Gallup, 1993) conducted for a Boston OPO shows that 85% of Americans were in support of organ donation, while other studies reported young people have positive views as well (Jafri & Tellis, 2001; Sanner, 1994). Although adults and teenagers have positive attitudes about donation, individuals have their own perspectives regarding the topic due to their up-bringing, experiences, religious beliefs, and knowledge base. And as much as individuals agree with the concept of granting consent to organ donation, there continues to be controversy surrounding the topic and barriers to successful transplants.

This study was a non-equivalent quasi experimental design. An experimental and a control group were used consisting of approximately 40 students per group. The curriculum consisted of a pre- and post-survey so comparisons could be made between the two groups and within the various demographics.

## Research Questions

The overarching research question that was examined was:

Q1: What factors do teenagers consider when making a decision to be willing to consent to become an organ donor at the time they receive their driver's permit or license for the first time?

This study examined the following variables: sources of information regarding organ donation; basic demographic information such as age, gender, ethnicity, religion, and parent's level of education; knowledge about organ donation; and willingness regarding organ donation. Based on these variables, other research questions included:

Q2: From what sources (family, school, media, etc.) do teenagers obtain knowledge about organ donation?

Q3: Does knowing someone (donor/recipient) increase willingness to consent to organ donation?

Q4: Are there significant differences regarding gender (male/female), ethnicity (white, Hispanic, etc.), and religion (Catholic, Jewish, etc.) among teenagers regarding willingness to consent to organ donation?

Q5: Is there a difference in grade point average between students who are willing to consent to organ donation and those who are not?

Q6: Is there a difference in knowledge between the experimental and control group (difference in score) regarding willingness to consent to organ donation?

Q7: What is the relationship between knowledge level and willingness to consent?

Q8: What is the relationship between knowledge level and perceived consent to organ donation?

Organ donation continues to be an intriguing topic and a societal issue where the demand is much greater than the supply. Most of the research regarding organ donation is based on surveys, with most of the surveys indicating the majority of people are in agreement with organ donation. However, there continues to be a shortage of needed organs (Gibson, 1996; O'Carroll, Dryden, & Hamilton-Barclay, 2011; Park et al., 2009; Wu, 2008). Although Gibson (1996)

suggests the problem of discrepancy lies with the various barriers that pertain to organ donation and not with the surveys themselves, the reality is that the supply will never meet the demand. Thinking or discussing the idea of organ donation is an abstract concept for most people. This is important to keep in mind when disseminating information and /or developing curricula for educational purposes. With the unrelenting need for organs, the long wait lists, and the number of deaths every year; organ donation needs to be continuously researched, including the various factors considered regarding granting consent.

### **Pilot Study**

A pilot study was conducted on June 26, 2013, to test the pre-survey instrument for understanding and appropriateness of the questions. All information collected was based on a one-time 30-minute session, consisting of the pre-survey, a discussion about the questions, and a discussion about what the process was like for the participants. The pilot study sample was similar to the sample that was used for the actual research study (e.g., male/female high school students).

The pilot sample consisted of 15 teenage students, 6 boys and 9 girls, who attended a local high school in Fort Collins, Colorado. The age range was from 14 to 16 years and included freshmen and sophomores. This group was targeted due to their recent or soon-to-be driving status, as they may have recently been introduced to the concept of organ donation for the first time. The survey took approximately seven minutes. After all participants were done, the instrument was reviewed for clarity and understanding; as the pilot study was mainly to assess the instrument, pilot study findings are not reported.

The survey used in the pilot study (Appendix G) was revised numerous times from the original form used in the original research (Spigner et al., 2002). The original research found

more than 50% of the students (N = 247) did not know the correct answers to 13 of 16 knowledge statements, and minorities were less likely to consent to organ donation. During this study, television was the number one source of information for students, while school was the second most common source of information regarding transplantation. The most common reasons students did not want to become a donor was the belief that the body should remain whole after death and personal fears about death. The researchers found that family communication is critical in the process of donation, and white/Caucasians were more likely to have discussed the topic compared to non-whites.

The purpose of the original study was to gather baseline data pertaining to knowledge and opinions about organ donation from urban high school students (Spigner et al., 2002). Although the original study did not use an intervention, the researchers did access health and science classes to examine consent regarding teens. The authors believe that a school-based curriculum could be a beneficial vehicle to increase awareness of organ donation. In the original study, concepts that were examined included general knowledge about organ donation and transplantation (Statements 1-16), personal experience (Questions 17-24), opinions regarding organ donation (Questions 25-29), and general demographic information (Questions 30-35). The original research accessed schools in Seattle (Washington) that were diverse in population. It is apparent that many of these variables continue to be factors regarding organ donation.

Based on the pilot study, four of the original statements on the original survey by Spigner et al. were modified to relate strictly to solid organs and not tissue (Statements 15, 17, 18, and 24), four of the original items were deleted due to being region specific (Statements 10, 22, 28, and 31), and two questions were added pertaining to my research questions (Statements 5 and 33). As the process of modifying the instrument progressed; condensing, deletions, and

additions were made to have relevance to the current study. Thus, a 31-item self-administered survey was developed.

### **Research Design**

The research was quantitative, and the design was a between-and-within subject quasi-experimental non-equivalent approach. Because the sample was not random, the specific approach was quasi-experimental, using a comparison group design with a control group (health class periods 1 and 3) and an experimental group (health class periods 2 and 4). The design was considered to be nonequivalent because the comparison groups could differ in some other variable or characteristic that was not being measured.

The experimental group received the treatment (education curriculum regarding organ donation) and was compared to the control group. The pre/post survey strengthened the research design. The questionnaires from the pre- and post-survey (Appendices H and I) were matched and numbered to maintain students' anonymity.

The revised survey used in this research contained 16 true/false knowledge statements (Statements 1-16), a question asking about one's source of information (Statement 17), personal experience (Statements 18-21), willingness about organ donation (Statement 22), consent (Statement 23), demographics (Statements 24-26), and general information (Statements 27-31).

During the school semester, students in the health classes study topics such as drugs and alcohol, sex education, and other wellness topics. The high school health teacher used a general consent form to include all topics that were studied through the semester (Appendix J). This study was approved by the Institutional Review Board (Appendix K).

## **Research Instrument**

The instrument used in this study was modified from the original version and from the pilot study version (Spigner et al., 2002). The original authors used 13 separate classrooms in three urban high schools in Seattle, Washington, for a total of 247 students. The original survey asked questions pertaining to organ and tissue transplantation and donation.

The instrument was selected due to its content validity. Statements 1-16 are asked at face value and directly elicit a response related to knowledge about organ donation, indicating the content is representative of the construct of knowledge (Gliner, Morgan & Leech, 2009). These statements assisted in measuring knowledge level. These statements are important and needed to answer the current research questions. For the purpose of this research, the statements pertained to solid organ transplantation and donation only.

## **Population and Sample**

The accessible population was all teenagers enrolled in health classes in one school district and one high school. The sample consisted of four health classes (two control/two experimental). All students have to take a health class as a graduation requirement with content areas including drugs, alcohol, sex education, and other wellness topics. This researcher accessed the four health classes during the spring of 2015, with approximately 40 students in the control group and 40 students in the experimental group.

The sample consisted of 9<sup>th</sup> to 12<sup>th</sup> grade students who attended a rural high school in northern Colorado. As of July, 2014, the high school consisted of approximately 840 students, with an age range of 14-19 years.

The school student population was divided nearly equally between males and females, 449 and 390, respectively. Five hundred twenty-three of the students were White, followed by 294 Hispanic/Latino students, 4 Asians, 3 African-Americans (not Hispanic), 2 Hawaiian

Pacific, 3 American Indian or Alaskan Native, and 10 identified as multiple races. Other demographics of the high school included: 43 English language learners, and 68 students on Individualized Education Plans.

The primary language spoken in most homes of the students was English (80%), and then Spanish (20%). Because the district was in a rural farming community, seasonal field work was available.

The high school served students from a neighboring town three miles away. The total population of the district was approximately 17,000 persons, with the school district having about 3,550 students. Of these 3,550 students, approximately 840 attended the high school.

### **Validity**

Although various researchers discuss different types of validity (Angen, 2000; Lather, 1991), they all pertain to the two primary types of validity: internal and external validity. According to researchers, external validity refers to the degree that findings can be generalized to other populations.

Measurement validity is the extent that a score is an accurate measure of what it states it is measuring, and research validity refers to the overall quality of the study. Construct validity is a feature of measurement validity and is when a researcher can show that the instrument is measuring a construct—in this situation, knowledge about organ donation (Gliner et al., 2009). According to Eisner (1991), validity is seen as credibility, and it allows one to be confident in the interpretations and the conclusions. The types of validity that were applicable to this study include both internal and external validity; specifically; concurrent validity, content validity, and face validity.



## **Internal Validity**

Because the research was survey research, using a pre/post intervention, there were various threats to the internal validity that included attrition (participants dropping out during the study), extraneous environmental events (e.g., one of the teachers currently on the waitlist), selection bias (participants were not randomly assigned), and instrumentation (inconsistency in the instrument or observations) (Shadish, Cook, & Campbell, 2002). In this study, attrition (three kids were not part of the post-survey due to leaving the class) and selection bias applied to the independent variable. The internal validity may be compromised by two factors: (a) the sensitivity surrounding the topic itself; and (b) self-reporting, which may lead to students responding in a more favorable manner than they really feel or think. They may do this to make themselves look good in the eyes of others. This phenomenon is called social desirability. This was minimized by having the students be anonymous and using their student identifications.

## **Reliability**

According to Cronbach (1990), reliability refers to consistency—in this case, consistency of the instrument. The instrument is considered reliable if it is developed in a way that can be measured over time. For example, if measured again, the results would display similar findings. Much of the research has studied similar variables, such as gender and ethnicity (Pierini et al., 2009; Rubens, 1996; Terrell, Mosley, Terrell, & Nickerson, 2004).

Methods to measure instrument reliability include: (a) split-half methods; (b) Cronbach's alpha; (c) test-retest; and (d) parallel forms (Gliner et al., 2009). The Cronbach coefficient alpha for this study for the knowledge items was a 0.6889. Reliability is important in research because one needs to know that the instrument can be used in the future to obtain consistency. This study

used the pre-survey/post-survey method for the independent variable of knowledge and the dependent variable of consent.

### **Data Collection and Procedures**

In the study, the procedures for data collection included having the students take the pre- and post-survey and identify themselves anonymously (no names), using their student identification number, matching (pre- and post- survey), and then numbering the participants in each group.

Objectives of the overall research were to disseminate accurate information, increase knowledge, and encourage discussion about organ donation. The student sample was divided into a control group (two health classes) and an experimental group (two health classes). Both groups were administered the pre-survey in the initial (introduction) class sessions. The objectives for this session were to explain the research, build rapport, review, and take the pre-survey. During this 30-minute session, the researcher and the research were introduced, the process of the research was discussed, an overview of the directions of the pre-survey was given, and the pre-survey was taken.

Noted observations during the pre-survey for the control group included that (a) students started to fill out the questionnaire before directions were complete; (b), one student asked a question that was addressed in the directions; (c), another student commented that she received her permit from another state, and she was not sure how to answer the survey. One student was very hesitant to indicate his student identification number, but said aloud that he would be using a certain number. Another student asked how they should fill out the survey if they did not have a permit or a license.

Noted observations during the pre-survey for the experimental group included that (a) one student stated his/her parents were divorced and asked how he/she should answer the parental education question; (b) a handful of students asked the teacher to look up their grade point average, she declined, and told the students to approximate; (c) one student told the teacher he was not religious and asked how he should answer the question; (d) one student asked what a recipient was (this indicated he did not read the first page of the survey).

One month later, the experimental group was given a specific curriculum related to organ transplantation and donation. The objectives at the beginning of the session were to inform the students about organ donation and to increase their awareness of the topic. The curriculum (Appendix L) session took approximately 45 minutes and included information regarding organ donation, a 20-minute video entitled “No Greater Love,” and a discussion about various scenarios. The purpose of the video was to increase awareness. Components of the video included an overview of organ and tissue donation and transplantation, answers to commonly asked questions, discussion of matching criteria, and present religious viewpoints. The video is a publication of the U.S. Department of Health and Human Services (2004). The classes were divided into groups of three to four students to discuss various scenarios (Appendix L) The objectives of the scenarios were to have the students use critical thinking skills regarding organ donation and discuss who and why someone should receive an organ.

Two weeks later (six for the control group), in the third (closing) session which took approximately 30 minutes, both the control and the experimental groups took the post-survey in their respective classes. During this session, the students took the post survey, participated in a group discussion and debriefed about the information, the topic, and the research itself.

All questionnaires and follow-up was administered during health classes. Both groups had the opportunity to have a debriefing session to ask questions related to the questionnaire and/or the research being conducted (this was part of Session 3 for the experimental group).

Observations that were noted during the second session (curriculum) included: (a) students in Class Period 2 were intently watching the video and not talking during the story of the firefighter; and (b) the class as a whole had more movement when medical professionals discussed the medical aspects of donation. The class was interested in what happened to the firefighter, asking if he eventually received an organ. In Class Period 4 (which was part of the experimental group), the class as a whole talked periodically during the video and appeared not to be as interested compared to the second-period class. No questions were asked by students in either class during the presentation of the information regarding organ donation, and students in Class Period 4 talked more in-depth regarding the scenarios.

Observations for the post-survey for all four classes included: (a) most students took less time on the post-survey; (b) a couple of students said they could not remember what identification number they used on the pre-survey; (c) during the debriefing, no questions were asked by students about organ donation or the research, although the researcher did ask questions pertaining to having discussions with their parents and if the students had any discomfort or distress during or because of the survey. None of the students indicated any stress.

### **Data Analysis**

Statistical analysis was conducted using SAS to compare groups. The purpose of this was to measure whether or not the education curriculum of organ donation had an influence on knowledge and consent of teenagers, and to determine differences and relationships regarding the variables.

Variables include demographics (gender, ethnicity, religion, grade point average, and parent's level of education), knowledge, personal experience, willingness, and consent. Some of these variables have been examined in earlier research (Siegel et al., 2011; Spigner et al., 2002; Thornton et al., 2006) and continue to be of interest. Demographic questions were answered with Items 24 and 25, addressing Research Questions 4 and 5. The statistical analysis that examined demographics was chi-square. Knowledge scores were determined by the number of correct responses from Statements 1-16. An increase in correct answers from the pre-survey to the post-survey would indicate an increase in knowledge about organ donation. Knowledge scores, Items 1-16, were used to examine Research Questions 6 and 7 and were analyzed using least square means. Because the variables of gender, ethnicity, religion, and parental level of education were stable and unlikely to change during this study, knowledge, willingness, and consent were the variables examined with the pre- and post-survey for the experimental and control group. Personal experience questions, which were Items 17-21, were looked at with Research Questions 2 and 3 and were analyzed using descriptive statistics. Factors that influence willingness related to consent consisted of survey Item 22 and were answered with Research Question 8 and analyzed using descriptive statistics as well. Consent, which is the focal variable, was examined through items 23 and 29 and will be answered with Research Questions 3 through 8. Factors influencing consent include knowledge statements (1-16) and demographic questions (24-25). Table 2 displays the variables of interest (knowledge, source, personal experience, willingness, consent, and demographics), survey items, research questions, and appropriate statistics for the study.

Scoring of the knowledge statements was based on the number of correct responses and a change in score from the pre-survey to the post-survey. Possible scores ranged from 0 to 16. Scoring for the source was based on a yes/no response to each listed source, and scoring for

personal experience was scored with a yes/no response to knowing a recipient, someone on the waitlist, or knowing a donor (living or deceased). Willingness was scored on a Likert scale, with a higher number indicating a higher level of willingness, and consent was scored with a yes, no, or I don't know response.

Table 2

*Variables of Interest*

Variable Items/Research Questions	Scoring	Statistic
Knowledge (Items 1-16; RQ 6-7): Is there a knowledge difference between the treatment and control group pre/post regarding willingness and consent? Is there a correlation between knowledge and consent?	Number of yes responses/number of no responses Change in scores	Least Square Means
Source (Item 17; RQ 2): From what sources (family, school, etc.) do teens obtain their knowledge?	Number of yes responses/number of no responses	Descriptive
Personal (Items 18-21; RQ 3): Does knowing someone (donor/recipient) correlate to willingness to consent?	Knowing a donor or recipient, yes/no	Descriptive
Willingness (Item 22; RQ 6-8): What variables influence willingness to consent?	Likert scale—higher number indicates stronger willingness	Least Square Means
Consent (Items 23, 28; RQ 3-8): If asked today, would you consent?	Yes/No/Don't know	Chi-Square
Demographic (Items 24-26; RQ 4-5): Age, gender, grade, ethnicity, GPA, parent's level of education.	N/A	Descriptive

All students, regardless of having or not having a permit or drivers' license, were compared. The scores between the control and the experimental group and the pre and post group regarding consent and willingness were analyzed using a chi-square and a Least Square Means. These were used to compare groups.

Chi-square tests compare proportions between two groups (e.g., proportions of males and females). A Chi-square test is used to determine if there are significant differences in frequencies in one or more categories, it measures the similarity of distributions (White & White, 2004).

Least square means are means for an effect (control/experimental or pre/post) that have been adjusted for the other effects. It calculates for missing data so it appears that missing data is included. The mean square is a result of dividing the sum of squares by the number of degrees of freedom. The mean square estimates the error of variance (Larson, 2008).

Student comments were collected and reviewed, comments ranged from indicating they would definitely become donors, to comments pertaining to being a donor only for a loved one or family member, to definite feelings of not liking organ donation in general as well as students stating they would not be willing to become donors.

## CHAPTER 4

### FINDINGS

Whether one agrees with organ donation or not, it continues to be a controversial and emotional topic. There are many factors to consider when choosing to become a donor. Supporters of organ donation have a lofty endeavor ahead of them in their attempts to disseminate information and increase awareness. There continues to be a lack of needed organs.

The participants in this study attended a rural high school in northern Colorado. The high school houses approximately 840 students, 9<sup>th</sup> through 12<sup>th</sup> grade. The participants were mostly 9<sup>th</sup> grade students (93%), with 53% being age 15 and close to 40% being 14. Forty-nine percent were males, and 51% were females. Seventy-one percent of the students were White, and 28 % were Hispanic. Of the participants, 72% did not yet have a driver's permit or license. Table 3 displays the demographic characteristics of the surveyed students. Some demographics do not represent 100 percent due to participants omitting the question (e.g., religion); other demographics exceed 100 percent due to participants indicating more than one response (e.g., ethnicity)



Table 3

*Demographic Characteristics of Students*

Characteristic	Control (N = 54) Mean Age = 14.43		Experimental (N = 48) Mean Age = 14.78	
	Number	%	Number	%
Gender				
Female	26	48	26	54
Male	27	50	22	46
Grade				
9	50	92	43	90
10	1	2	2	4
11	1	2	1	2
12	1	2	2	4
Religion				
Catholic	19	35	15	31
Other	16	30	13	27
Not Applicable	11	20	13	27
Non-denominational	2	2	5	10
Mormon	1	2	3	6
Jewish	0	0	0	0
Ethnicity				
White	41	76	37	77
Hispanic	21	39	19	40
American Indian/Alaskan Native	3	6	5	10
Black	4	7	2	4
Asian	2	4	1	2
Language spoken at home				
English	43	80	39	81
Bilingual	8	15	5	10
Spanish	2	4	2	4

Table 3 (continued)

Characteristic	Control (N = 54) Mean Age = 14.43		Experimental (N = 48) Mean Age = 14.78	
	Number	%	Number	%
Level of education				
Father:				
Grade school	1	2	0	0
Middle school	2	4	4	8
High school	13	24	15	31
Tech school	1	2	2	4
Some college	9	17	5	10
College degree	6	11	6	13
Graduate degree	8	15	5	10
Don't know	8	15	7	15
Mother:				
Grade school	1	2	0	0
Middle school	0	0	0	0
High school	10	19	16	33
Tech school	2	4	1	2
Some college	14	26	5	10
College degree	5	9	7	15
Graduate degree	9	17	8	17
Don't know	9	17	9	19
Have Permit	9	17	11	23
Have License	1	2	3	6

### Knowledge

Because the students were asked not to guess on the knowledge statements, many of the responses to individual items were *Don't know*; therefore, many of the knowledge statements had a high *Don't know* response rate. The predominance of the students answered most of the statements incorrectly on the pre-survey, indicating a lack of accurate information about organ donation. Table 4 illustrates the percentages of correct and incorrect pre-survey and post-survey student responses to each knowledge statement, along with the percentages of *Don't know*. The majority of the students got most of the statements (11 out of 16) on the pre-survey incorrect.

There were a couple statements that most students knew correctly on the pre-survey. These were related to knowing that blood type was important (6) and organs can come from living donors (10). The percentage of correct responses was greater for each statement on the post-survey, except the question related to auto accidents (9), which most participants responded *Don't know* on the pre-survey, and the few who answered correctly on the pre-survey often changed their response to *Don't know* on the post-survey.

Table 4

*Responses to Knowledge Statements*

Statement	Pre-survey (N = 102)			Post-survey (N = 99)		
	N/% Correct	N/% Incorrect	N/% Don't Know	N/% Correct	N/% Incorrect	N/% Don't Know
1. Transplant survival rates today are very high. (T)	48/47	1/1	52/51	60/61	9/10	28/28
2. Almost one-half of the persons waiting for organ transplants in the United States are from minority groups. (T)	17/17	15/15	68/67	30/30	10/10	56/57
3. African-Americans wait longer for kidney transplants than Caucasians/Whites. (T)	8/8	29/28	64/63	16/16	41/41	39/40
4. Asian-Americans wait longer for kidney transplants than Caucasians/Whites. (T)	3/3	29/29	69/68	6/6	50/51	41/41

Table 4 (continued)

Statement	Pre-survey (N = 102)			Post-survey (N = 99)		
	N/% Correct	N/% Incorrect	N/% Don't Know	N/% Correct	N/% Incorrect	N/% Don't Know
5. Latinos have a chronic liver disease rate that is twice that of Caucasians/Whites (T)	75/74	6/6	20/20	74/75	9/10	14/14
6. Blood type doesn't make any difference for getting a donated organ. (F)						
7. Most organs received by minorities are donated by Caucasians. (T)	15/15	14/14	72/71	18/18	23/23	57/58
8. People wouldn't need transplants if they took better care of themselves. (F)	58/57	18/17	23/23	63/64	13/13	20/20
9. More people die from automobile accidents and gunshot wounds than from heart disease each year. (T)	32/31	20/20	49/48	23/23	29/29	42/42
10. A recipient can receive an organ from a living donor. (T)	83/81	2/2	16/16	78/79	4/4	12/12
11. A recipient's chance of surviving a transplant operation today is pretty low. (F)	53/52	3/3	46/45	62/62	9/10	25/25
12. Transplant recipients can live more than 10 years after a transplant operation. (T)	38/37	2/2	62/61	56/57	4/4	34/34

Table 4 (continued)

Statement	Pre-survey (N = 102)			Post-survey (N = 99)		
	N/%	N/%	N/% Don't	N/%	N/%	N/% Don't
	Correct	Incorrect	Know	Correct	Incorrect	Know
13. A national computer system matches and distributes donated organs to the persons who are the sickest and to those who have been waiting the longest. (T)	42/41	7/7	51/50	54/55	8/8	35/35
14. Sometimes, organs can be sold on the black market for money in the United States. (F)	7/7	52/51	41/40	15/15	50/51	23/23
15. Rich or famous people can receive organs before the people with the most need. (F)	36/35	17/17	49/48	44/44	22/22	27/27
16. A transplant operation has less than a 50/50 chance of allowing the recipient to return to normal activities. (F)	12/12	25/25	65/64	18/18	31/31	45/45

For example, 97% of students did not know that Asia Americans wait longer for a kidney than Whites, and 91% of students did not know that African Americans wait longer for a kidney than Whites. When asked about blood type and if it was important for donations, 74% of students correctly stated that it was. When asked if a national computer system matched and distributed organs to the most ailing and those who have been waiting the longest, 42% of the students answered correctly. Only 8% of the students correctly answered false when asked if organs could be bought and sold on the black market in the United States. All noted responses were based on the pre-survey items. The pre-survey scores (ranging from 0 to 16) were similar

for the experimental (0 to 9) and control group (0 to 10) and were not significantly different based on least square means ( $p = 0.559$ ). The change in post-survey scores (ranging from 0 to 16) for the experimental group shows a significant difference from the control group ( $p = .0009$ ). Table 5 illustrates a Type III F Test for knowledge with the Least Square Means and the Difference of the Least Square Means; these tests compute means of fixed effects. This test was used to display a comparison between the control and the experimental groups along with comparisons on the pre- and post-survey scores for the knowledge statements. Least Square Means was used to compare the effect; treatment = control and experimental, and time = pre- and post-survey; \* =  $<.0001$ . The Type III F Test contains tests for the significance of each of the fixed effects (e.g., pre-/post-survey, experimental/control) specified in the model. It shows the means for the control and the experimental groups were similar (5.4 and 5.1 respectively) on the pre-survey regarding knowledge, but the experimental group was significantly different from the control group regarding knowledge on the post-survey (7.6 and 5.7 respectively).

Table 5

*Knowledge Scores*

Type III F-Test				
Effect	Num DF	Den DF	F-Value	Pr> F
Treat	1	115	2.96	0.0878
Time	1	82	25.30	<.0001
Treat*Time	1	82	14.20	0.0003

Table 5 (continued)

Least Square Means									
Effect	Treat	Time	Estimate	Standard Error	DF	T-Value	Pr> /t/		
Treat	Control	—	5.6172	(0.3052)	115	18.41	<.0001		
Treat	Exp	—	6.382	(0.3277)	115	19.49	<.0001		
Time	—	Post	6.7243	(0.2676)	82	25.13	<.001		
Time	—	Pre	5.2810	(0.2643)	82	19.98	<.0001		
Treat*Time	Control	Post	5.7982	(0.3646)	82	15.90	<.0001		
Treat*Time	Control	Pre	5.4361	(0.3619)	82	15.02	<.0001		
Treat*Time	Exp	Post	7.6504	(0.3918)	82	19.53	<.0001		
Treat*Time	Exp	Pre	5.1260	(0.3852)	82	13.31	<.0001		
Differences of Least Square Means									
Effect	Treat	Time	Treat	Time	Estimate	Standard Error	DF	T Value	Pr> /t/
Treat* Time	Control	Post	Control	Pre	0.3621	0.3940	82	0.92	0.3607
Treat* Time	Control	Post	Exp	Post	-1.8521	0.5352	82	-3.46	0.0009
Treat* Time	Control	Pre	Exp	Pre	0.3101	0.5285	82	0.59	0.5589
Treat* Time	Exp	Post	Exp	Pre	2.5244	0.4173	82	6.05	<.0001

Note. Least square means was used to compare the effect; treatment = control or experimental, and time = pre-or post-; \* = 0.36 for control and 2.52 for experimental

## Source of Information

Today teenagers are inundated with information from various types of technology. The days of waiting to get information from the nightly news are long gone. One can access the Internet to get information as it is happening, and applications notify as soon as events occur. Table 6 shows that of the eight likely sources of information on transplantation and donation, news media (TV, radio, newspapers, and public service announcements) were most prevalent, with 68% of students indicating they heard about organ transplantation and donation from this source on the pre-survey. Family ranked second as the source for information on the topic, with 67% of students selecting it; school ranked the third most prevalent source for transplantations and donation, with 65% of students selecting it. One can see that in the post-survey, school and friends together were much more prevalent than family.

Table 6

*Sources of Information Regarding Organ Donation Pre/Post-survey*

Source	Pre-survey (%) (N = 102)		Post-survey (%) (N = 99)	
	Yes	No	Yes	No
	N/%	N/%	N/%	N/%
News media (TV, radio, newspaper, public service announcements)	69/68	33/32	72/76	23/24
Family	66/67	33/33	65/70	28/30
School	66/65	35/35	83/86	14/14
Entertainment (TV programs, movies, concerts)	61/60	40/40	69/73	25/27



Table 6 (continued)

Source	Pre-survey (%) (N = 102)		Post-survey (%) (N = 99)	
	Yes N/%	No N/%	Yes N/%	No N/%
Internet (Wikipedia, websites, donation sites, YouTube)	56/56	44/44	60/64	34/36
Social media (Face book, Instagram)	44/44	55/56	54/57	40/43
Friends	33/33	67/67	51/55	42/45
Religion	20/20	80/80	18/20	73/80

### Personal Experience

Knowing someone who has been a recipient, on the waitlist, or a living or deceased donor may influence one's consent. Many of the students (70-82%) did not know anyone who had been through the experience, either as a recipient or a donor. Approximately one-third (29%) of the students knew someone who was a recipient, 14% knew someone on the waitlist, and 39% of the students knew a donor (living or deceased). Table 7 represents the pre-survey percentages of students who knew someone on the waitlist, a recipient, or a donor (living or deceased).

Table 7

*Personal Experiences with Organ Donation*

Experience and Relationship	Student Responses
	(%) (N = 98) N/%
Has received an organ:	
No one	69/70
Family	14/14
Other	9/9
Friend	6/6
Is or has been on the waitlist:	
No one	81/85
Family	9/9
Other	3/3
Friend	2/2
Living donor:	
No one	78/79
Family	10/10
Other	8/8
Friend	3/3
Deceased donor:	
No one	80/82
Family	13/13
Other	4/4
Friend	1/1

**Willingness**

There are a variety of factors that influence students' willingness to become a donor. The factors related to willingness regarding organ donation are illustrated in a Likert scale (1-5, with a higher score indicating more willingness) in Table 8. The most commonly selected responses

pertaining to willingness included: “I could save a family member” and “I could save a life.”

Fifty percent of pre-survey students (N = 102) selected this statement with a high level of willingness (5); 54% of students selected it in the post survey with a high willingness rating (5).

Six of the nine statements had a higher level of willingness on the post survey.

Table 8

*Factors Influencing Willingness*

How Willing Would I be to Consent to be an Organ Donor (Influencing Factor)	Pre-survey Willingness Rating (%)					Post-survey Willingness Rating (%)				
	1	2	3	4	5	1	2	3	4	5
I could save a life.	3	9	16	23	50	2	6	21	17	53
It's an act of kindness/altruism.	7	6	22	32	33	3	9	19	32	36
It's against my religion.	46	10	13	8	22	47	9	22	4	18
I'm afraid of the surgery or procedure.	16	13	34	16	22	14	4	41	20	20
I think about how my body would look after donation.	22	11	27	22	19	17	16	26	19	21
I think my organs would only go to rich people.	43	18	26	3	11	31	26	28	7	9
I think doctors may not try as hard to make me well if I carry a card saying I want to be an organ donor.	36	14	31	7	12	23	19	31	14	13
I think my body should remain whole after death.	17	10	28	18	27	10	14	28	17	30
I could save a family member.	3	2	4	15	76	1	3	8	11	77

Table 9 displays that, overall, there were no significant differences in willingness from the pre-survey group compared to the post survey group ( $p = 0.322$ ) for either the control or the experimental groups. Table 9 shows the effect comparisons, comparing treatment by time, which was experimental group compared to control group and pre and post survey comparisons with the means and standard error. The pre-survey mean for the control group was 3.1914 and the post-survey mean for the control group was 3.3700. The pre-survey mean for the experimental group was 3.2844 and the post-survey mean for the experimental group was 3.3281. Although there was a change in means for both groups, the treatment by time ( $p = 0.322$ ) is not significant.

Table 9

*Pre-survey/Post-survey Willingness Comparison*

Type III F-Test				
Effect	Num DF	Den DF	F-Value	Pr> F
Treat	1	115	0.04	0.8514
Time	1	82	2.69	0.1049
Treat*Time	1	82	0.99	0.3222

Table 9 (continued)

Least Square Means									
Effect	Treat	Time		Estimate	Standard Error	DF	T-Value	Pr> /t/	
Treat	Control	—		3.2807	0.0925	115	35.46	<.0001	
Treat	Exp	—		3.3062	0.0995	115	32.21	<.0001	
Time	—	Post		3.3491	0.0762	82	43.90	<.001	
Time	—	Pre		3.2379	0.0755	82	42.84	<.0001	
Treat*Time	Control	Post		3.3700	0.1039	82	32.44	<.0001	
Treat*Time	Control	Pre		3.1914	0.1033	82	30.89	<.0001	
Treat*Time	Exp	Post		3.3281	0.1118	82	29.78	<.0001	
Treat*Time	Exp	Pre		3.2844	0.1104	82	29.76	<.0001	
Differences of Least Square Means									
Effect	Treat	Time	Treat	Time	Estimate	Standard Error	DF	T Value	Pr> /t/
Treat	Control	—	Exp	—	-0.0255	0.1359	115	-0.19	0.8514
Time	—	Post	—	Pre	0.1112	0.0677	82	1.64	0.1049
Treat*									
Time	Control	Post	Control	Pre	0.1787	0.0932	82	1.92	0.0588

Table 9 (continued)

Differences of Least Square Means									
Effect	Treat	Time	Treat	Time	Estimate	Standard Error	DF	T Value	Pr>  t
Treat* Time	Control	Post	Exp	Post	0.0419	0.1526	82	0.28	0.7839
Treat* Time	Control	Post	Exp	Pre	0.0856	0.1516	82	0.57	0.5736
Treat* Time	Control	Pre	Exp	Post	0.1367	0.1522	82	-0.90	0.3718
Treat* Time	Control	Pre	Exp	Pre	0.0930	0.1512	82	-0.62	0.5400
Treat* Time	Exp	Post	Exp	Pre	0.0436	0.0984	82	0.44	0.6586

\* = Treatment by time.

### Consent

There are various factors that influence consent in organ donation. In this study, variables that may contribute to consent included: knowledge, personal experience, willingness, and demographics. Demographic variables included age, gender, GPA, ethnicity, and parental level of education. Table 10 shows the percentages of students who were willing to grant consent pre-survey compared to post-survey. Based on the data, 37 percent of students responded yes to consent on the pre-survey and 46 percent responded yes to consent on the post-survey. Almost 10 percent of the participants changed their responses, indicating they would be a donor. Seventeen percent of students indicated they did not want to be donor on the pre-survey, with a decrease to 10 percent indicating they did not want to grant consent on the post-survey. This shows that the participants were more willing to grant consent based on the post-survey data. Forty-four percent of the participants indicated they were unsure if they would grant consent on

the pre-survey, with 41 percent of unsure responses on the post survey indicating they had changed their response to granting consent or not granting consent. The percentage of participants who omitted answering the question asking about consent remained the same from the pre-survey to the post-survey, with two percent. The change in student responses from pre-survey to post-survey was not significant 0 = omitted, 1 = yes to consent, 2 = no to consent, 3 = unsure. Although the knowledge scores were higher on the post-survey for the experimental group (Chi-Square  $p$ -value for the control group was 0.7341 and 0.4267 for the experimental group), they did not influence consent.

Table 10

*Percentage Consent Comparison between Pre/Post-survey Experimental Control Groups*

Response	Pre-survey (N = 102) N/%	Post-survey (N = 99) N/%
Yes	38/37	46/46
No	17/17	10/10
Unsure	45/44	41/41
Omitted	2/2	2/2
Group		
Experimental (N = 94)		
1-Yes	40	50
2-No	25	15
3-Unsure	35	33
0-Omitted	0	2

Table 10 (continued)

Response	Pre-survey (%) (N = 102)	Post-survey (%) (N = 99)
Control (N = 107)		
1-Yes	35	43
2-No	9	6
3-Unsure	52	49
0-Omitted	4	2

Table 11

*Comparisons between the Pre/Post and Experimental/Control Regarding Consent*

Statistic	DF	Value	Prob
Control group			
Chi-Square	3	1.2791	0.7341
Likelihood ratio Chi-Square	3	1.2914	0.7312
Experimental group			
Chi-Square	3	2.7804	0.4267
Likelihood ratio Chi-Square	3	3.1818	0.3644

### Demographics

Demographics include age, gender, grade, religion, ethnicity, and parental level of education. Tables 12-14 illustrate the percentages of willingness of responses according to the various demographics. Males were 49% of the participants, (N = 102) and females 51%.



Twenty-nine percent of the participants reported that their father’s level of education was a high school diploma, 15% didn’t know what level of education their father had, and 13% of the students reported that their father had a college or graduate degree. For mothers, it was similar: 27% of mothers had a high school education, 19% didn’t know their mother’s level of education, and 18% had some college.

The data on religion were unable to be analyzed due to over 60% of the students indicating *other, non-denomination, or Not Applicable*. Seventy-one percent were White, 28% Hispanic, and 1% Asian.

Table 12

*Percentages of Students’ Willingness to Consent by Gender*

Response	Male (N = 49)		Female (N = 52)		Total (N = 101)	
	N	%	N	%	N	%
Yes	11	22	27	52	38	
No	12	24	5	10	17	
Unsure	24	49	20	38	44	
Omitted	2	4	0	0	2	
Total	49	49	52	51	101	100

Table 13

*Percentages of Students 'Willingness to Consent by Ethnicity*

Response	White (N = 54)		Hispanic (N = 21)		Total (N = 76)	
	N	%	N	%	N	%
	Omitted	1	2	1	5	2
Yes	24	44	5	24	29	38
No	8	15	4	19	12	16
Unsure	21	39	11	52	33	43
Total	54		21		76	100.00

Table 14

*Percentages of Students 'Willingness to Consent by Religion*

Religion	Response								Total (N)
	Omitted		Yes		No		Unsure		
	N	%	N	%	N	%	N	%	
Catholic	1	3	11	32	4	12	18	53	34
Other	1	3	10	34	7	24	11	38	29
Not applicable	0	0	11	42	5	19	10	38	26
Nondenominational	0	0	3	43	1	14	3	43	7
Mormon	0	0	3	75	0	0	1	25	4
Total	2		38		17		43		100

Table 13 displays consent by ethnicity. It shows Whites were more willing to consent compared to the other minority groups, it also displays that Whites are almost as unsure about consent. Table 14 shows consent by religion. Catholics responded '*unsure*' more often than any other religion, with almost 53% percent, while 75% of Mormons responded '*yes*'. Students who indicated their religion as '*other*' were the least likely to consent to organ donation.

In summary, the pre-survey for the control and the experimental group regarding knowledge scores were similar without a significant difference. However, there was a significant difference in the post-survey knowledge score for the experimental group (pre-survey mean = 5.13; post-survey mean = 7.65). There were no significant differences in the pre- and post-survey responses regarding willingness and consent. Although the knowledge score increased on the post-survey for the experimental group, indicating more knowledge about organ donation, this increase did not influence more students in the experimental group to be willing to consent on the post-survey. There was a significant difference regarding gender, with females being more willing to consent. Although research shows that minorities are less likely to donate (Russell, Robinson, Thompson, Perryman & Jacob Arriola, 2011) due to a lack of trust in medical professionals, premature declaration of death, and racism (Callender, Bayton, & Yeager, 1982) in this study there was not a difference. There also was not a difference by ethnicity regarding consent.

## **CHAPTER 5**

### **RESULTS**

This chapter is a summary of the overall study and discusses the data presented in Chapter 4. It addresses findings, methodology, theory, limitations, recommendations for future research, and concluding remarks.

The majority of the general public is in favor of organ donation (Gallup, 1993; Siminoff et al., 2001). Radecki and Jaccard (1997) found the general public has a positive attitude toward organ donation; slightly more than one-fourth of people actually signed some form of a donor card. King et al. (2012) found that approximately 90% of the general public was in favor of donation, while 30% were registered donors. However, consent for organ recovery continues to be a crucial barrier for individuals and families. Youngner (1990) suggests that society is actually hesitant about the subject and, in the abstract, it is valuable, but when applied personally, individuals find it distasteful. Every day 17 people die waiting for an organ transplant, and the number of people on the waiting list has more than tripled since 2005 exceeding 82,000 (OPTN, 2004). Although the United States has a volunteer system, some believe that policy should change to operate under a presumed consent (opt out) model like some European countries (Spain and Belgium). The purpose of this study was to gain insights on the perspective that adolescents have regarding organ donation and the factors that contribute to their willingness to grant consent to become an organ donor. Little research has been done to measure knowledge about organ donation among teenagers (Spigner et al., 2002).

## Research Questions and Findings

The overarching research question that was examined was:

Q1: What factors do teenagers consider when making a decision to be willing to consent to become an organ donor at the time they receive their driver's permit or license for the first time?

This study examined the following variables: sources of information regarding organ donation; basic demographic information such as age, gender, ethnicity, religion, and parent level of education; knowledge about organ donation; and willingness regarding organ donation.

Based on these variables, other research questions were posed.

Q2: From what sources (family, school, media, etc.) do teenagers obtain knowledge about organ donation?

The findings show that teens had heard about organ donation more often from news media (TV, radio, newspapers, and public service announcements), followed by family, school, entertainment, Internet, social media, friends, and, lastly, religious related organizations. Based on this, family was responded to more often than technology, in general, and friends.

Q3: Does knowing someone (donor/recipient increase willingness to consent to organ donation?

Twenty students (of 41) who knew someone responded 'yes' to becoming a donor, and 21 students who knew someone responded 'no' or 'unsure' to consent. Of the participants who know someone, 49 percent consented to become a donor, 10 percent did not give consent, and 41 percent indicated they were unsure if they would grant consent to be a donor. Therefore, knowing someone did not influence consent.

Q4: Are there significant differences regarding gender (male/female), ethnicity (white, Hispanic, etc.), and religion (Catholic, Jewish, etc.) among teenagers regarding willingness to consent to organ donation?

For demographics, there was a significant difference regarding gender. Females (27%) were more willing to grant consent compared to males (11%). There was no difference regarding ethnicity. Religion was not analyzed.

Q5: Is there a difference in grade point average between students who are willing to consent to organ donation and those who are not?

The students who indicated 'yes' to consent indicated an average GPA of 3.27. The students who indicated 'no' to consent had an average GPA of 2.59.

Q6: Is there a difference in knowledge between the experimental and control group (difference in score) regarding willingness to consent to organ donation.

The knowledge scores were similar on the pre-survey for the experimental and the control group. The knowledge score on the post-survey increased for the experimental group, showing a significant change compared to the control group.

Q7: What is the relationship between knowledge level and willingness to consent?

Although the knowledge score increased for the experimental group on the post-survey, this did not suggest that more students were willing to consent.

Q8: What is the relationship between knowledge level and perceived consent to organ donation?

There was no correlation between knowledge level and consent. Although knowledge increased in the experimental group on the post-survey, it did not increase the number of students who would consent to become an organ donor.

## **Summary of Findings**

The major findings consisted of comparing the pre-and post-surveys and the control and the experimental groups. The control and the experimental groups were similar on the knowledge scores for correct/incorrect statements on the pre-survey; however, the experimental group (7.6504) showed a significant difference in the post-survey compared with the control group (5.7982). There was not a significant difference in willingness and consent in the pre-survey and the post-survey for either group. Although knowledge increased in the experimental post-survey, it did not influence willingness or consent. More females were willing to consent to become organ donors, and there was no significant difference in ethnicity among teenagers. Students who were willing to consent to organ donation had a higher grade point average compared to students who were unwilling to grant consent. These findings are similar to research regarding knowledge and gender differences, but different in regard to ethnicity. Spigner et al., (2002) found that minorities were less likely to grant consent, however this study found no difference.

## **Theory**

Theory used in this research included ecosystems, Erikson's (1963) stages of development, and the prototype willingness model. Bronfenbrenner's (1979) ecosystem suggests that individuals are influenced by a variety of systems. The most influential and direct system is the micro system. This environment is the one that directly and immediately impacts individuals. It includes family, friends, and others who have regular contact with individuals. News media was selected most often as a source of information for students regarding organ donation; family was the second most-listed source. This is evidence that family is still a source of information and a direct influence on teens. The topic of organ donation is often depicted in the media (Feeley & Vincent, 2007; Harrison et al., 2008). In this study, news media was the

most frequently indicated source of information. This illustrates that news media is still a vital source of information regarding organ donation and other topics. As recently as March 31, 2015, there was an article in the *Denver Post* (p. 4A) about a man who put a magnetic sign on his truck to advertise that his wife was in need of a kidney transplant.

Erikson's (1963) psychosocial developmental stages suggest that at each stage there is a conflict that needs to be resolved. During adolescence (12-18 of age), the transition from childhood to adulthood is most important. At this stage, the conflict is identity versus role confusion. At this time, individuals are examining who they are and who they want to be. They are trying to find their role and identify with a sense of who they are. It should be noted that most of the students were at the lower end of the age range, 14 to 15. Comments from the students were based from the pre- and the post- survey. One student stated, "I'm not against it, but I can't say I like it either," while another reported, "I don't believe in organ donation...but I would do it only if my family member had a chance of surviving." One student stated, "I would be an organ donor," another responded, "God gave us the will, so I will give to others," and another stated, "Donating organs saves lives, and I think everyone should be a donor." Other comments were, "I would like to keep my body with everything together," "I don't know anything about this," and "I don't think I could live a normal life."

The prototype willingness decision model has to do with intentions, norms, past behavior, and the model or image of what a donor looks like. It is based on spontaneous decision making. This theory is compatible with organ donation in regard to the spontaneity of a response when teens are asked to be an organ donor for the first time when receiving a driver's permit or license. Based on the survey, it is not compatible in regards to the prototype or image of a donor. Some student responses indicated that they saw themselves as organ donors at the time of their



death and not as living donors. Simmons et al. (1987) suggest the decision-making process for living-related donors has three criteria. It is moral decision making, which represents spontaneous or unplanned choice making. It is a deliberate, conscious, or mindful choice. Lastly, it is postponement (for living donors), where the donor delays making a decision and only becomes a donor after everyone else has been ruled out for various reasons. In this situation, the donor takes the position of not having to make a decision until there are no other options or possible donors; however, this still indicates a decision. Postponement may be evident through the high number of students who gave an '*unsure*' response (44% pre-, 41% post-). By responding '*unsure*,' one does not have to commit either way.

Myths that surround the topic of organ donation include the thought that if medical staff knows one is a donor, doctors may be less likely to try to save one's life and remove organs before one is truly dead (Arriola et al., 2005;Haustein& Sellers, 2004). This mistrust leads some to believe in unjust allocations of organs and leads some to believe that the wealthy and/or famous are more likely to receive a transplant (Haustein & Sellers, 2004; Morgan et al., 2008). Teens had similar thoughts in regards to myths. Almost 52% of teens thought that organs could be sold on the black market, and close to 17% of students said that the rich and famous receive organs before those with the most need.

The variables in this research are similar to previous studies. Findings are parallel to past literature as well. Earlier research consistently refers to the lack of knowledge that most individuals have regarding organ donation. This was the case in this research. The majority of the 16 knowledge statements were answered incorrectly (pre-survey = 12 incorrect, post-survey = 9 incorrect) by most of the participants.

Researchers (Pierini et al., 2009; Radecki & Jaccard, 1997) found approximately 75-85% of teenagers are interested and possibly willing to become donors, but like adults, approximately one-fourth have actually given consent. In this study, close to 44% of teens responded *unsure* to granting consent to become an organ donor, while 37% responded *yes* on the pre-survey.

Research shows that men are less likely to donate and less likely to have discussions about organ donation (Thompson et al., 2003). Other researchers found teenage girls were more likely to have discussed their intentions to donate with family members compared to boys (Thornton et al., 2006). Wells (2005) found similar results, indicating women having a higher willingness to donate compared to males. This research found that teenage girls (52%) were more likely than their male counterparts (22%) to consent to organ donation.

Although studies have shown that ethnicity plays a role in granting consent (McNamara et al., 1999; Park et al., 2009; Rubens, 1996), in this study there was no significant difference regarding ethnicity.

Level of education may be a factor regarding willingness to consent. It has been suggested that the more education one has attained, the more willing one is to grant consent (Conesa et al., 2003) although level of education does not apply to teens. This research indicated that grade point average may be a factor regarding consent. Students who were willing to grant consent had a grade point average of 3.27, while students who were not willing to grant consent had a grade point average of 2.59.

### **Limitations**

Because the topic of organ donation is sensitive and evokes emotion, it may be difficult for teens to think about their death and the ramifications of being a donor. Self-reporting was used, and in this situation, was the only way to obtain responses. One limitation with self-

reporting is participants may not have been honest with their responses. Social desirability may have led to individuals inflating their willingness or their consent to organ donation. Another limitation is that it is unknown whether this research encouraged or brought on family discussions about one's wishes, the hope was that the study provided an opportunity for teens to discuss organ donation with their families. Lastly, another limitation was that a convenience sample was used, rather than a random sample.

### **Recommendations**

Ways in which this study could be improved are to do randomization of groups, use a population that can generalize more to the general populace, and ask questions that are more easily understood, for example knowledge statement number nine. Implications for school social work practice included having an opportunity to discuss the topic with the health teacher and encouraging school personnel to make the topic of organ donation part of the health curriculum or the biology curriculum. This can provide a vehicle for the dissemination of information regarding organ donation in an educational setting. Another recommendation would be to consider revising the instrument; although the survey was explained in each class period for the pre- and the post-survey, the Likert scale may have been confusing for students. Revisions to specific statements or questions may possibly lead to a better understanding for students.

### **Concluding Remarks**

Although teenagers under the age of 18 may be in favor of organ donation, many students in this study were undecided regarding consent. It is ultimately the next-of-kin, usually parents, who choose to grant consent for their child to be an organ donor. Research suggested that family discussions are crucial for increasing the actual transplantation rate (Sirois et al., 2005: Wu,

2008). Proponents of organ donation state that school-based education may be effective to increase awareness and knowledge of the topic (Spigner et al., 2002); perhaps for teenagers under the age of 18, it would be more effective to educate students and parents, since it is they who will make the final choice. Perhaps not only should the teens be exposed to a school-based curriculum, but maybe when some teens take their driver's education classes, the parents should have some education on the topic as well. It is important to remember that potential teen donors come from tragic and unexpected accidents (Holtkamp, 1997) where a neurological determination of death (brain dead) is needed. Because not everyone involved (medical professionals, family, etc.) has the same definition for brain death, donation opportunities may be missed. It is important to keep in mind that even if donor numbers did increase, there still has to be certain circumstances (brain death) that exist to allow for donations to occur.

With the idea of presumed consent and some thinking this may be a solution to the constant shortage of organs, it still has the same implications of choice. One can opt out and say no to donation. Although some like this philosophy, others feel it is too invasive and should not be implemented because it takes away choice.

In the beginning of the study, the thought was that teens are a population who should be targeted for awareness of organ donation, and although knowledge about organ donation has been studied, it has been suggested the more knowledge one has the more willing one is to consent to become a donor; in this study knowledge did not influence consent. Because of this, knowledge may be beneficial for the sake of knowledge, but it is also helpful in clarifying misconceptions and myths. Implications for action would be to have the DMV encourage students to have a discussion with their family about organ donation at the time they receive a

permit and ask them if they want to consent to be a donor at the time they receive a driver's license.

On the surface, organ donation may be a very logical and practical concept with lifelong benefits for some; however, when you take into consideration the events that would have to occur to have an organ donation available, it has a completely different meaning. When faced with this critical decision, it has an even more profound meaning for the family of the deceased, the family members making the choice, the family members who may disagree with the choice, the recipient and the family of the recipient. This no longer is a thought one has from a distance; it becomes an emotional decision that impacts many people lifelong.

Throughout this process, my own willingness to be an organ donor oscillated for various reasons. Perhaps the issue of willingness and consent regarding organ donation has more to do with the timing or the circumstances of one's life, rather than the variables that have been studied.

## REFERENCES

- About Donation and Transplantation. (n.d.). Retrieved June 20, 2011, from Organdonor.gov  
<http://www.organdonor.gov/aboutStatsFacts.asp>
- Ahn, J. (2010). *The influence of social network sites on high school students' social and academic development* (Unpublished doctoral dissertation). Retrieved from University of Southern California. Los Angeles, CA.
- Alvaro, E. M., Jones, S. P., Robles, A. S. M., & Siegel, J. T. (2005). Predictors of organ donation behavior among Hispanic Americans. *Progress in Transplantation, 15*(2), 149-156.
- Angen, M. J. (2000). Evaluating interpretive inquiry: Reviewing the validity debate and opening the dialogue. *Qualitative Health Research, 10*(3), 378-395.
- Anker, A. E., & Feeley, T. H. (2011). Asking the difficult questions: Message strategies used by organ procurement coordinators in requesting familial consent to organ donation. *Journal of Health Communication, 16*, 643-659.
- Arriola, K. R., Perryman, J. P., & Doldren, M. (2005). Moving beyond attitudinal barriers: Understanding African Americans' support for organ and tissue donation. *Journal of the National Medical Association, 97*, 339-350.
- The Associated Press. (2013, June 17). Cheney thankful for "miracle" of health with heart transplant. *The Denver Post*, p. A12.
- The Associated Press. (2013, June 5). Sebelius won't intervene in Philly girl's transplant case. *The Denver Post*, p. A15.
- Aujoulat, I., Schwering, K. L., & Reding, R. (2011). Living-related donation: A challenge

- to adolescent transplant recipients who transit from parental care to self-managed care. *Child: Care, Health and Development*, 38(1), 146-148.
- Banevicius, M. (1992). *An investigation of cadaver organ donor families three years after donation: A pilot study* (Master's thesis), Yale University School of Nursing, New Haven, CT.
- Barber, K., Falvey, S., Hamilton, C., Collett, D., & Rudge, C. (2006). Potential for organ donation in the United Kingdom: Audit of intensive care records. *British Medical Journal*, 332, 1124-1127.
- Barcellos, F. C., Araujo, C. L., & Da Costa, J. (2005). Organ donation: A population-based study. *Clinical Transplantation*, 19, 33-37.
- Barnett, A. H., Blair, R. D., & Kaserman, D. L. (1992). Improving organ donation: Compensation versus markets. *Inquiry*, 29(3), 372-378.
- Bill Would Make Coloradoans Organ Donors by Default*. (2011, July 29). Retrieved from: colorado-organ-donor-bill\_n\_811272.html  
<http://huffingtonpost.com/2011/01/19/colorado-organ-donor-bill>
- Bires, M. H. (1999). Comparison of consent rates between hospital-based designated requestors and organ procurement coordinators. *Journal of Transplant Coordination*, 9(3), 177-180.
- Black, T., Blumenthal, J., Lassiter, J., Smith, W., Tisch, S. (Producer), & Muccino, G. (Director). (2008). *Seven Pounds* [Motion picture]. Los Angeles: Columbia Pictures.
- Blau, J., & Abramovitz, M. (2007). *The dynamics of social welfare policy*. New York: NY. Oxford University Press.

- Boulware, L. E., Ratner, L. E., Cooper, L. A., Sosa, J. A., LaVeist, T. A., & Powe, N. R. (2002). Understanding disparities in donor behavior: Race and gender differences in willingness to donate blood and cadaveric organs. *Medical Care, 40*(2), 85-95.
- Bradley, B. A., & Brooman, P. M. (1980). Panorama's lost transplants. *Lancet, 2*(8206), 1258-1259.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, NJ: Harvard University Press.
- Bruzzo, P. (2010). Financial incentives for organ donation: A slippery slope toward organ commercialism? *Transplantation Proceedings, 42*, 1048-1049.
- Burroughs, T. E., Hong, B. A., Kappel, D. F., Freedman, B. K. (1998). The stability of family decisions to consent or refuse organ donation: Would you do it again? *Psychosomatic Medicine, 60*(2), 156-162.
- Callender, C. O., Bayton, J. A., Yeager, C. (1982). Attitudes among blacks toward donating kidneys for transplantation: A pilot project. *Journal of the National Medical Association, 74*(6), 807-809.
- Caplan, A. (1984). Sounding board: Ethical and policy issues in the procurement of cadaver organs for transplantation. *New England Journal of Medicine, 311*, 981-983.
- Caplan, A. (2008). Organ transplantation. In M. Crowley (Ed.), *From birth to death and bench to clinic: The Hastings Center bioethics briefing book for journalists, policymakers, and campaigns*, (pp. 129-132). Garrison, NY: The Hastings Center.
- Carey, A., & Gonzalez, A. (2015, March 30). Organ donations. *USA Today*, p. B6.
- Chapa, J. (1992). *Hispanics and organ donation: Prospects, obstacles, and recommendations*. Unpublished manuscript, School of Public Affairs. University of Texas, Austin, TX.



- Cheung, A. H. S., Alden, D. L., & Wheeler, M. S. (1998). Cultural attitudes of Asian-Americans toward death adversely impact organ donation. *Transplantation Proceedings*, 30, 3609 - 3610.
- Cleiren, M., & Van Zoelen, J. (2002). Postmortem organ donation and grief: A study of consent, refusal and wellbeing in bereavement. *Death Studies*, 26, 837-849.
- Colorado Organ Donor Legislation Pulled*. (2011, July 29). Retrieved from colorado-organ-donor-legi\_n\_81249.html <http://www.huffingtonpost.com/2011/01/21/colorado-organ-donor-legi>
- Conesa, C., Rios, A., Ramirez, P., Rodriguez, M. M., Rivas, P., Canteras, M., & Parrilla, P. (2003). Psychosocial profile in favor of organ donation. *Transplantation Proceedings*, 35(4), 1276-1282.
- Cronbach, L. J. (1990). *Essentials of psychological testing* (5<sup>th</sup>ed.). New York, NY: HarperCollins.
- Davis, R. (2004, October 25). Online organ match raises ethical concerns. *USA Today*.
- DeJong, W., Franz, H. G., Wolfe, S. M., Nathan, H., Payne, D., Reitsma, W., & Beasley, C. (1998). Requesting organ donation: An interview study of donor and nondonor families. *American Journal of Critical Care*, 7(1), 13-23.
- Donate Life Colorado. (2013). Facts and questions/Did you know. Retrieved from <http://www.donatelifecolorado.org>
- Donath, J., & Boyd, D. (2004). Public displays of connection. *BT Technology Journal*, 22(4), 71-82.

- DuBois, J. M., & Anderson, E. E. (2006). Attitudes toward death criteria and organ donation among healthcare personnel and the general public. *Progress in Transplantation, 16*(1), 65-73.
- DuBois, J. M., & Schmidt, T. (2003). Does the public support organ donation using higher brain death criteria? *Journal of Clinical Ethics, 14*(1-2), 26-36.
- Eisner, E. W. (1991). *The enlightened eye: Qualitative inquiry and the enhancement of educational practice*. New York, NY: Macmillan.
- Emmerich, T., Finn, M., Furst, S., Kaufman, M., Pokorny, D., Tropper, M. (Producer), & Cassavetes, N. (Director). (2009). *My Sister's Keeper* [Motion picture]. Los Angeles, CA: New Line Cinema.
- Erikson, E. H. (1963). *Childhood and society* (2nd ed.) New York, NY: Norton.
- Feeley, T. H., & Servoss, T. J. (2005). Examining college student's intentions to become organ donors. *Journal of Health Communication, 10*, 237-249.
- Feeley, T. H., & Vincent, D. (2007). How organ donation is represented in newspaper articles in the United States. *Health Communication, 21*, 125-131.
- Gallup Organization (Gallup). (1993). *The American public's attitudes toward organ donation and transplantation*. Boston, MA: The Partnership for Organ Donation.
- Gallup Organization (Gallup). (2005). *2005 National survey of organ and tissue donation attitudes and behaviors*. Washington, DC: Health Resources and Services Administration.
- Gauldin, A. (2015, March 31). Getting out the message. *The Denver Post*, p. A4.

- Gibbons, F. X., Gerrard, M., Blanton, H., & Russell, D. W. (1998). Reasoned action and social reaction: Willingness and intention as independent predictors of health risk. *Journal of Personality and Social Psychology, 74*, 1164-1180.
- Gibson, V. (1996). The factors influencing organ donation: A review of the research. *Journal of Advanced Nursing, 23*(2), 353-356.
- Gliner, J. A., Morgan, G. A., & Leech, N. L. (2009). *Research methods in applied settings*. New York, NY: Routledge.
- Harris, C. E., & Alcorn, S. P. (2001). To solve a deadly shortage: Economic incentives for human organ donation. *Issues in Law & Medicine, 16*(3), 213-233.
- Harrison, T. R., Morgan, S. E., & Chewning, L. V. (2008). The challenges of social marketing of organ donation: News and entertainment coverage of donation and transplantation. *Health Marketing Quarterly, 25*, 33-65.
- Haustein, S. V., & Sellers, M. T. (2004). Factors associate with (un)willingness to be an organ donor: Importance of public exposure and knowledge. *Clinical Transplantation, 18*(2), 193-200.
- Health Resources and Services Administration. (2005, January 18-20). *Organ donation break through collaborative*. Presentation at the 2005 Learning Session 2. Birmingham, AL.
- Healy, K. (2006). *Last best gifts: Altruism and the market for human blood and organs*. Chicago, IL: University of Chicago Press.
- Hirvas, J., Enckell, M., Kuhlback, B., & Pasternack, A. (1976). Psychological and social problems encountered in active treatments of chronic uraemia. The living donor. *Acta Medica Scandinavica, 200*, 17-20.

- Holtkamp, S. (1997). The donor family experience: Sudden loss, brain death, organ donation, grief and recovery. In J. Chapman, M. Deierhoi, & C. Wight (Eds.), *Organ and tissue donation for transplantation*, (p. 304-322). New York, NY: Oxford University Press.
- Hyde, M. K., & White, K. M. (2010). Are organ donation communication decisions reasoned or reactive? A test of the utility of an augmented theory of planned behavior with the prototype/willingness model. *British Journal of Health Psychology*, *15*, 435-452.
- Institute of Medicine (IOM). (2006). *Organ donation: Opportunities for action*. Washington, DC: National Academy Press.
- Jafri, T. & Tellis, V. (2001). Attitudes of high school students regarding organ donation. *Transplantation Proceedings*, *33*, 968-969.
- Janis, I. L., & Mann, L. (1977). *Decision making: A psychological analysis of conflict, choice, and commitment*. New York, NY: Free Press.
- Karger, H. J., & Stoesz, D. (2010). *American social welfare policy: A pluralist approach* (6th ed.). Boston, MA: Allyn & Bacon.
- Kaserman, D. (2002). Markets for organs: Myths and misconception. *Journal of Contemporary Health Law and Policy*, *18*(2), 567-581.
- Kaserman, D. L., & Barnett, A. H. (2002). *The U. S. organ procurement system: A prescription for reform*. Washington, DC: AEI Press.
- Kennedy, I., Sells, R. A., Daar, A. S., Guttman, R. D., Hoffenberg, R., Lock, M., . . . Tilney, N. (1998). The case for “presumed consent” in organ donation. *Lancet*, *351*(9116), 1650-1652.

- King, A. J., Williams, E. A., Harrison, T. R., Morgan, S. E., & Havermahl, T. (2012). The "Tell Us Now" campaign for organ donation: Using message immediacy to increase donor registration rates. *Journal of Applied Communication Research, 40*, 229-246.
- Lam, W. A., & McCullough, L. B. (2000). Influence of religious and spiritual values on the willingness of Chinese-Americans to donate organs for transplantation. *Clinical Transplantation, 14*, 449-456.
- Larson, M. G. (2008). Statistical primer for cardiovascular research. *Circulation, 117*, 115-121.
- Lather, P. (1991). *Getting smart: Feminist research and pedagogy with/in the post-modern*. New York, NY: Routledge.
- Little, T. D., & Bovaird, J. A., Card, N.A. (2007). *Modeling ecological and contextual effects in longitudinal studies of human development*. Mahwah, NJ: Lawrence Erlbaum Associates.
- Lock, M. (1996). Deadly disputes: Ideologies and brain death in Japan. In S.J., Youngner, R. C., Fox, & L. J. O'Connell (Eds.), *Organ Transplantation* (pp. 142-167). Berkeley, CA: University of California Press.
- Long, T., Sque, M., & Payne, S. (2006). Information sharing: Its impact on donor and non-donor families' experiences in the hospital. *Progress in Transplantation, 16*(2), 144-149.
- Maloney, G., & Walker, I. (2000). Messiahs, pariahs, and donors: The development of social representations of organ transplants. *Journal for the Theory of Social Behaviour, 30*(2), 203-227.
- Manuel, A., Solberg, S., & MacDonald, S. (2010). Organ donation experiences of family members. *Nephrology Nursing Journal, 37*(3), 229-236.
- Martyn, S. R., Wright, R., & Clark, L. L. (1989, March/April). Required request revisited. *Hastings Center Report, 19*, 44.

- McGregor, J. L., Verheijde, J. L., & Rady, M. Y. (2008). The entertainment media framing of organ donation: Secondhand reality balancing the ideological bias of education campaigns. *Health Communication, 23*(4), 394-395.
- McNamara, P., Guadagnoli, E., Evanisko, M. J., Beasley, C., Santiago-Delpin, E. A., & Callender, C.O. (1999). Correlates of support for organ donation among three ethnic groups. *Clinical Transplant, 13*(1) 45-50.
- Merrill, J. P., Murray, J. E., Harrison, J. H., & Guild W. R. (1956). Successful homotransplantations of the human kidney between identical twins. *Journal of the American Medical Association, 160*(4), 277-282.
- Midwest Transplant Network. (2013). General education guide/frequently asked questions. Retrieved from <http://www.mtn.org>
- Morgan, S. E., Harrison, T. R., Afifi, W. A., Long, S. D., & Stephenson, M. T. (2008). In their own words: The reasons why people will (not) sign an organ donor card. *Health Communication, 23*, 23-33.
- Morgan, S. E., Harrison, T. R., Afifi, W. A., Long, S. D., Stephenson, M. T., & Reichert, T. (2005). Family discussions about organ donation: How the media is used to justify opinions and influence others about donation decisions. *Clinical Transplantation, 19*, 674-682.
- Morgan, S. E., Harrison, T. R., Chewning, L. V., DiCorcia, M., & Davis, L. (2007). Entertainment (mis)education: The framing of organ donation in entertainment television. *Health Communication, 22*, 143-151.

- Morgan, S. E., King, A. J., Smith, J. R., & Ivic, R. (2010). A kernel of truth? The impact of television storylines exploiting myths about organ donation on the public's willingness to donate. *Journal of Communication, 60*, 778-796.
- Morgan, S., & Miller, J. (2002). Communicating about gifts of life: The effective of knowledge, attitudes, and altruism on behavior and behavioral intentions regarding organ donation. *Journal of Applied Communication Research, 30*(2), 163-178.
- Morris, J. A., Slaton, J., & Gibbs, D. (1989). Vascular organ procurement in the trauma population. *Journal of Trauma, 29*(6), 782-788.
- Nathan, H. M., Conrad, S. L., Held, P. J., McCullough, K. P., Pietroski, R. E., Siminoff, L. A., & Ojo, A. O. (2003). Organ donation in the United States. *American Journal of Transplantation, 3*(4), 29-40.
- National Conference of State Legislatures. (2013, March 12). *State leave laws related to medical donors*. Retrieved from <http://www.ncsl.org/issues-research/labor/state-leave-laws-for-medical-donors.aspx>
- The National Organ Transplant Act of 1984, Pub L. 98-507, 98 Stat. 2339-2348 (Oct. 19, 1984).
- Neades, B. (2009). Presumed consent to organ donation in three European countries. *Nursing Ethics, 16*(3), 267-282.
- Nilsson, M., Persson, L. O., & Forsberg, A. (2008). Perceptions of experiences of graft rejections among organ transplant recipients striving to control the uncontrollable. *Journal of Clinical Nursing, 17*, 2408-2417.
- O'Carroll, R. E., Dryden, J., & Hamilton-Barclay, T. (2011). Anticipated regret and organ donor registration--A pilot study. *Health Psychology, 30*(5), 661-664.

The Omnibus Budget Reconciliation Act of 1985, Pub L. 99-272, 100 Stat. 82 (April 7, 1986).

*Organ Donation: Encyclopedia of Everyday Law*. (n.d.). Legislation. Retrieved June 7, 2011, from <http://www.enotes.com/everyday-law-encyclopedia/organ-donation>

*Organ Donor Bill Stirs Controversy*. (2011, January 19). Retrieved July 4, 2013, from [denverpost.com. blogs.denverpost.com/thespot/2011/01/19/organ-donor-bill-stirs-controversy/21178/](http://denverpost.com/blogs.denverpost.com/thespot/2011/01/19/organ-donor-bill-stirs-controversy/21178/)

Organ Donor History. (n.d.). Retrieved June 20, 2011, from New York Organ Donor Network <http://www.donatelifeny.org/all-about-transplantation/organ-transplant-history>

OPTN (Organ Procurement and Transplantation Network). (2004). Wright DH Survey Report. Retrieved from: <http://www.optn.org>

OPTN (Organ Procurement and Transplantation Network) (2006). National Data Reports. [Online]. Available: <http://www.optn.org/latestData/step2.asp?> [Accessed June 10, 2014].

Park, H. S., Smith, S. W., & Yun, D. (2009). Ethnic differences in intention to enroll in a state organ donor registry and intention to talk with family about organ donation. *Health Communication, 24*, 647-659.

The Patient Self Determination Act of 1990,[section 4206 and 4751] of the COBRA Act., Pub L.101-508 (Enacted on Nov. 5, 1990).

Pearson, I. Y., Bazeley, P., Spencer-Plane, T., Chapman, J. R., & Robertson, P. (1995). A survey of families of brain dead patients: Their experiences, attitudes to organ donation and transplantation. *Anaesthesia and Intensive Care, 23*(1), 88-95.



- Pelletier, M. (1992). The organ donor family member's perception of stressful situations during the organ donation experience. *Journal of Advanced Nursing, 17*, 90-97.
- Petechuk, D. (2006). *Organ transplantation*. Westport, CT: Greenwood Press.
- Piccoli, G. B., Soragna, G., Putaggio, S., Burdese, M., Bergamo, D., Mezza, E., ... Segoloni, G. P. (2004). To give or to receive? Opinions of teenagers on kidney donation. *Transplantation Proceedings, 36*, 448-449. doi: 10.1016/j.transproceed.2004.02.066
- Pierini, L., Valdez, P., Pennone, P., Verges, J., Melano, R., Cabezas, V. . . . Robles, D. (2009). Teenager donation: Investigation of 848 high school students. *Transplantation Proceedings, 41*, 3457-3459.
- Plasma Donation. (2013). Facts about plasma donation. Retrieved from:  
[www.donatingplasma.org/facts/](http://www.donatingplasma.org/facts/)
- Presidential Council on Bioethics. (2006). *Organ Transplantation Policies and Policy Reforms*. Retrieved from  
<http://www.http://bioethics.georgetown.edu/pcbe/background/crowepaper.html>
- Radecki Breitkopf, C. (2006). Perceived consequences of communication organ donation wishes: An analysis of beliefs about defending one's decision. *Psychology and Health, 21*(4), 481-497.
- Radecki, C., & Jaccard, J. (1997). Psychological aspects of organ donation: A critical review and synthesis of individual and next-of-kin donation decisions. *Health Psychology, 5*, 565-580.
- Rene, A. A., Viera, E., Daniels, D., & Santos, Y. (1994). Organ donation in the Hispanic population: Donde estanellos? *Journal of the National Medical Association, 86*, 13-16.

- Rivis, A., Sheeran, P., & Armitage, C. J. (2006). Augmenting the theory of planned behavior with the prototype willingness model: Predictive validity of actor versus abstainer prototypes for adolescents' health-protective and health-risk intentions. *British Journal of Health Psychology, 11*, 483-500.
- Rubens, A. J. (1996). Racial and ethnic differences in students' attitudes and behavior toward organ donation. *Journal of the National Medical Association, 88*(7), 417-421.
- Russell, E., Robinson, D. H. Z., Thompson, N. J., Perryman, J. P., Jacob Arriola, K. R. (2012). Distrust in the healthcare system and organ donation intentions among African Americans. *Journal of Community Health, 37*, 40-47.
- Sanner, M. A. (1994). A comparison of public attitudes toward autopsy, organ donation and anatomic dissection: A Swedish survey. *Journal of the American Medical Association, 271*, 284-288.
- Shadish, W. R., Cook, T. D., & Campbell, D. T. (2002). *Experimental and quasi-experimental designs for generalized causal inference*. Boston, MA: Houghton Mifflin.
- Shafer, T. J., Ehrle, R. N., Davis, K. D., Durand, R. E., Holtzman, S. M., Van Buren, C. T., Crafts, N. J., & Decker, P. J. (2004). Increasing organ recovery from level 1 trauma centers: The in-house coordinator intervention. *Progress in Transplantation, 14*(3), 250-263.
- Shaw, R. (2011). The ethical risks of curtailing emotion in social science research: The case of organ transfer. *Health Sociology Review, 20*(1), 58-69.

- Siegel, J. T., Alvaro, E. M., & Hohman, Z. P. (2011). "Can you spare an organ?": Exploring Hispanic Americans' willingness to discuss living organ donation with loved ones. *Health Communication, 26*, 754-764.
- Siminoff, L. A., Gordon, N., Hewlett, J., & Arnold, R. M. (2001). Factors influencing families' consent for donation of solid organs for transplantation. *Journal of the American Medical Association, 286*(1), 71-77.
- Siminoff, L. A., Mercer, M. B., & Arnold, R. (2003). Families' understanding of brain death. *Progress in Transplantation, 13*(3), 218-224.
- Siminoff, L. A., & Saunders Sturm, C. M. (2000). African-American reluctance to donate: Beliefs and attitudes about organ donation and implications for policy. *Kennedy Institute of Ethics Journal, 10*(1), 59-74.
- Simmons, R. G., Marine, S. K., & Simmons, R. L. (1987). *Gift of life: The effect of organ transplantation on individual, family, and societal dynamics*. New Brunswick, NJ: Transaction.
- Sirois, B. C., Sears, S. F., & Marhefka, S. (2005). Do new drivers equal new donors? An examination of factors influencing organ donation attitudes and behaviors in adolescents. *Journal of Behavioral Medicine, 28*(2), 201-212.
- Spigner, C., Weaver, M., Cardenas, V., & Allen, M. D. (2002). Organ donation and transplantation: Ethnic differences in knowledge and opinions among urban high school students. *Ethnicity and Health, 7*(2), 87-101.
- Szabo, L. (2013, July 2). After 2<sup>nd</sup> transplant, a new debate. *USA Today*, pp. 3D

- Tabarrok, A. (2009). *Life-Saving incentives: Consequences, costs and solutions to the organ shortage*. Retrieved from <http://www.econlib.org/library/Columns/y2009/Tabarroklifesaving.html>
- Terrell, F., Mosley, K. L., Terrell, A. S., & Nickerson, K.J. (2004). The relationship between motivation to volunteer, gender, cultural mistrust, and willingness to donate organs among Blacks. *Journal of National Medical Association*, 96(1), 53-60.
- Thompson, N. M., Knudson, R., & Scully, G. (1997). Education in schools. In J. Chapman, M. Deirhoi, & C. Wight (Eds.), *Organ and tissue donation for transplantation* (pp. 400-411). New York, NY: Oxford University Press.
- Thompson, T. L., Robinson, J. D., & Kenny, R. W. (2003). Gender differences in family communication about organ donation. *Sex Roles*, 49(11-12), 587-596.
- Thornton, J. D., Wong, K. A., Cardenas, V., Curtis, J. R., Spigner, C., & Allen, M. D. (2006). Ethnic and gender differences in willingness among high school students to donate organs. *Journal of Adolescent Health*, 39(2), 266-274.
- Thornton, J. D., Wong, K. A., Spigner, C., & Allen, M. D. (2010). Effects of classroom education knowledge and attitudes regarding organ donation in ethnically diverse urban high schools. *Clinical Transplant*, 24, 784-793.
- Truog, R. D. (1997). *Is it time to abandon brain death?* *Hastings Center Report*, 27(1), 29-37.
- Uniform Anatomical Gift Act. (1968, 1987, 2006). Pub L. 10-123.
- Uniform Anatomical Gift Act. (2010). Retrieved June 7, 2011, from [anatomicalgiftact.org](http://www.a-o-t-a.org/uniform-anatomical-gift-act.html)
- United Network for Organ Sharing (UNOS). (2005). *About transplant centers*. Retrieved June 14, 2013, from: <http://www.unos.org/whoWeAre/transplantCenters.asp>

- United Network for Organ Sharing (UNOS). (2013). *Organ Data*. Retrieved July 7, 2014, from <http://www.unos.org/Data>
- U.S. Department of Health and Human Services (2004). *No Greater Love.organdonor.gov*
- U. S. Department of Health & Human Services. (2013). Timeline of Historical Events. <http://www.orgndonor.gov/legislation/>
- Verheijde, J. L., Rady, M. Y., & McGregor, J. L. (2007). The United States Revised Uniform Anatomical Gift Act (2006): New challenges to balancing patient rights and physician responsibilities. *Philosophy, Ethics, and Humanities in Medicine*, 2(19), 241-249.
- Verheijde, J. L., Rady, M. Y., McGregor, J. L., & Friederich-Murray, C. (2009). Enforcement of presumed-consent policy and willingness to donate organs as identified in the European Union survey: The role of legislation in reinforcing ideology in pluralistic societies. *Health Policy*, 90, 26-31.
- Vinokur, A. D., Merion, R. M., Couper, M. P., Jones, E. G., & Dong, Y. (2006). Educational web-based intervention for high school students to increase knowledge and promote positive attitudes toward organ donation. *Health Education Behavior*, 33, 773-786.
- Warren, N. A. (2002). Critical care family members' satisfaction with bereavement experiences. *Critical Care Nurse Quarterly*, 25(2), 54-60.
- Weaver, M., Spigner, C., Pineda, M., Rabun, K. G., & Allen, M. D. (2000). Knowledge and opinions about organ donation among urban high school students: Pilot test of a health education program. *Clinical Transplantation*, 14(4), 292-303.
- Weiss, A. H. (1996). Asking about asking: Informed consent in organ donation research. *IRB: A Review of Human Subjects Research*, 18, 6-10.

- Weizer, N., Weizman, A., Shapira, Z., Yussim, A., & Munitz, H. (1989). Suicide by related kidney donors following the recipients' death. *Psychotherapy and Psychosomatics*, 51, 216-219.
- Wells, J. A. (2005). *National survey of organ donation: 2005 preliminary results*. Paper presented at the Institute of Medicine Workshop on Increasing Rates of Organ Donation. Washington, DC.
- Wendler, D., & Dickert, N. (2001). The consent process for cadaveric organ procurement: How does it work? How can it be improved? *Journal of the American Medical Association*, 285(3), 329-333.
- West, R., & Burr, G. (2002). Why families deny consent to organ donation. *Australian Critical Care*, 15(1), 27-32.
- Wheeler, M. S., O'Friel, M., & Cheung, A. H. S. (1994). Cultural beliefs of Asian-Americans as barriers to organ donation. *Journal of Transplant Coordination*, 4, 146-150.
- Witte, R. S. & Witte, J. (2004). *Statistics*. Hoboken, NJ: John Wiley & Sons. Inc.
- Why Donate. (n.d.) Retrieved June 20, 2011, from Organdonor.gov  
<http://www.organdonor.gov/why.asp>
- Woo, K. T. (1992). Social and cultural aspects of organ donation in Asia. *Annals of the Academy of Medicine, Singapore*, 21, 421-427.
- Wu, A. M. S. (2008). Discussion of posthumous organ donation in Chinese families. *Psychology, Health & Medicine*, 13(1), 48-54.
- Youngner, S. J. (1990). Organ retrieval can we ignore the dark side? *Transplantation Proceedings*, 22(3), 1014-1015.

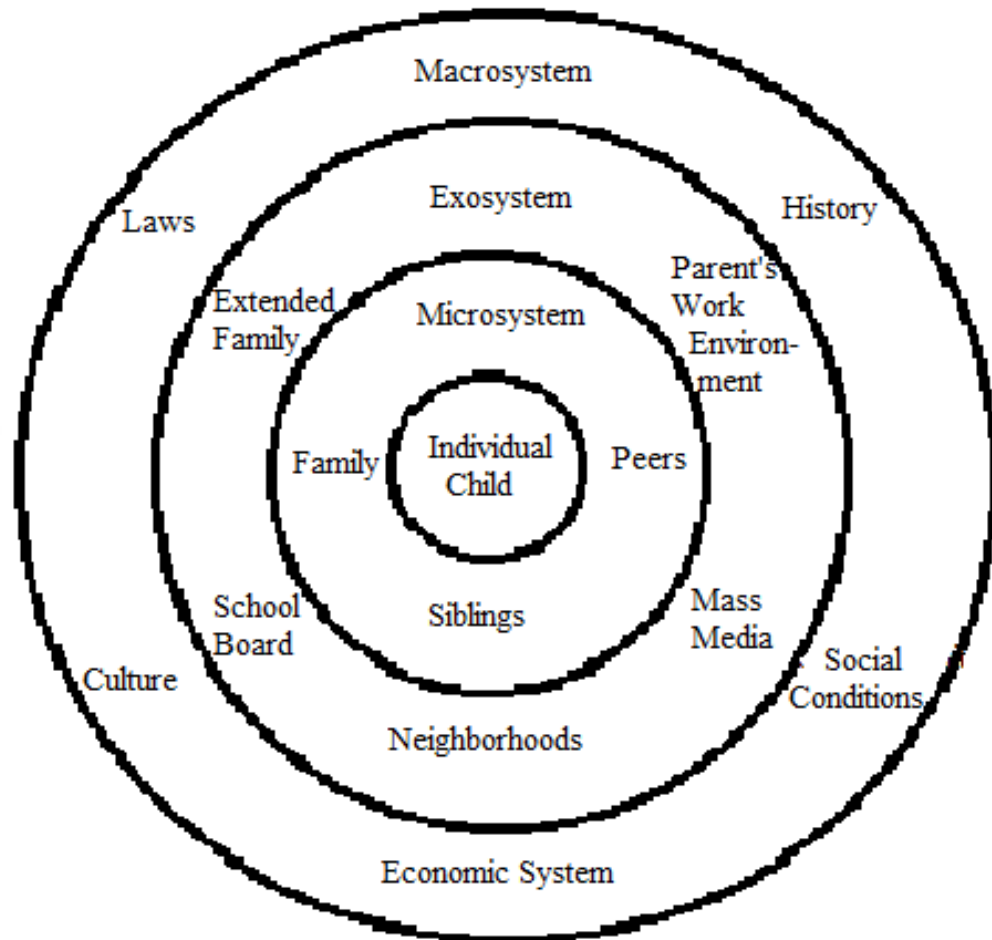
Youngner, S. J., & Arnold, R. M. (1993). Ethical, psychosocial, and public policy implications of procuring organs from non-heart-beating cadaver donors. *Journal of the American Medical Association*, 269(21), 2769-2774.

Yuen, C. C., Burton, W., Chiraseveenuprapund, P., Elmore, E., Wong, S., Ozuah, P., & Mulvihill, M. (1998). Attitudes and beliefs about organ donation among different racial groups. *Journal of the National Medical Association*, 90(1), 13-18.

Zink, S. (2004). The presumptive approach to consent for organ donation. Retrieved from <http://www.presumptivity.com/files/9.%20Introducion.ppt>

APPENDIX A

DIAGRAM OF ECOSYSTEM



Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*.



## APPENDIX B

### ERIKSON'S PSYCHOSOCIAL DEVELOPMENTAL STAGES

<b>Years</b>	<b>Virtue</b>	<b>Psycho Social Crisis</b>	<b>Significant Relations</b>	<b>Existential Question</b>	<b>Example</b>
0–2	Hopes	Basic trust vs. mistrust	Mother	Can I trust the world?	Feeding, Abandonment
2–4	Will	Autonomy vs. shame	Parents	Is it okay to be me?	Toileting
4–5	Purpose	Initiative vs. guilt	Family	Is it okay for me to do, move and act?	Exploring
5–12	Competence	Industry vs. inferiority	Neighbors	Can I make it in the world of people and things?	School/sports
13–19	Fidelity	Identity vs. role confusion	Peers, role model	Who am I? What can I be?	Social relations
20–24	Love	Intimacy vs. isolation	Friends, partners	Can I love?	Romance
25–64	Care	Generosity vs. stagnation	Household, coworkers	Can I make my life count?	Work/parenting
65-death	Wisdom	Ego integrity vs. despair	Mankind	Is it okay to have been me?	Reflect on life

Erikson, E. H. (1963). *Childhood and Society* (2<sup>nd</sup> ed.)

## APPENDIX C

### TIMELINE OF ORGAN DONATION/ TRANSPLANT EVENTS

#### The 1860s

**1869**—First skin transplant.

#### The 1900s

**1906**—First transplant of a cornea.

#### The 1950s

**1954**—First successful kidney transplant. A living donor gave a kidney to his identical twin.

#### The 1960s

**1960**—First successful kidney transplant performed between siblings who were not twins.

**1962/1963**—First kidney, lung, and liver transplants recovered from deceased donors, indicating a multi-organ transplant.

**1963**—First organ recovery from a brain dead donor.

**1966**—First successful pancreas transplant performed.

**1967**—First successful liver transplant.

—First U.S. heart transplant performed.

**1968**—Uniform Anatomical Gift Act drafted by the National Conference of Commissioners on Uniform State Laws; established the Uniform Donor Card as a legal document of gift in all 50 states, identified the types and priority of individuals who could donate a deceased person's organs, and enabled anyone over 18 to legally donate his or her organs upon death.

—The first organ procurement organization (OPO) was established, New England Organ Bank based in Boston.

—First definition of brain death based on neurological criteria developed by a Harvard Ad Hoc Committee.

—First successful bone marrow transplant performed.

### The 1970s

**1976**—Discovery cyclosporine's ability to suppress the immune system, helping to prevent the rejection of transplanted organs.

### The 1980s

**1980**—Uniform Determination of Death Act (UDDA) defines death as either irreversible cessation of circulatory and respiratory functions or irreversible cessation of all functions of the brain, including the brain stem.

**1981**—Uniform Determination of Death Act (UDDA), a draft state law developed by the National Conference on Uniform State Laws, in cooperation with the American Medical Association (AMA), the American Bar Association (ABA), and the President's Commission on Medical Ethics

—First combined heart/lung transplant performed.

**1983**—National Organ and Tissue Donor Awareness Week first declared by Congress, Senate Joint Resolution 78.

—First successful single lung transplant with significant recipient survival (more than 6 years).

—Surgeon General C. Everett Koop convenes the first workshop on solid organ procurement for transplant.

—Food and Drug Administration approves cyclosporine which can improve transplant outcomes as its immunosuppressive qualities lessen the potential for organ rejection.

**1983/1984**—First successful lung and heart/liver combined transplant performed.

**1984**—The National Organ Transplant Act passed by Congress prohibits the selling of human organs, establishes the [Organ Procurement and Transplantation Network](#) to ensure fair and equitable allocation of donated organs, and the [Scientific Registry of Transplant Recipients](#) to conduct ongoing evaluation of the scientific and clinical status of organ transplantation. It also provided for grants for the establishment, initial operation, and expansion of organ procurement organizations.

**1985**—Public Law 99-272, The Omnibus Reconciliation Act of 1985, April 8, 1986, required States have written standards with regard to coverage of organ transplants in order to qualify for federal payments under Title XIX of the Social Security Act.

**1986**—Required Request legislation. The Omnibus Budget Reconciliation Act of 1986 required hospitals to have policies in place for offering all families of deceased patients the opportunity to donate their loved one's organs.

— First contract for establishment and operation of the OPTN is awarded by the U.S. Department of Health and Human Services (HHS) to the United Network for Organ Sharing (UNOS). The OPTN provides services for equitable access and allocation of organs and sets the membership criteria and standards for transplant centers in the U.S.

**1987**—First successful intestine transplant performed.

—Medicare pays for heart transplants performed at hospitals that meet criteria set by the Health Care Financing Administration (now Centers for Medicare and Medicaid Services).

**1988**—First split-liver transplant surgery. This procedure enables two recipients to each receive a portion of one donated liver.

**1989**—First successful small intestine transplant.

## The 1990s

**1990**—First successful living donor lung transplant was performed.

—Nobel Prize awarded to Dr. Joseph E. Murray and Dr. E. Donnall Thomas, pioneers in kidney and bone marrow transplants, respectively. Dr. Murray performed the first successful kidney transplant (1954) and Dr. Thomas performed the first bone marrow transplant (1968).

—Medicare pays for liver transplant (that meet specific medical criteria) performed at approved hospitals.

**1991**—Surgeon General Antonia Novella convenes a national workshop on increasing organ donation.

**1995**—First living donor kidney was removed through laparoscopic surgical methods that result in a small incision and easier recovery for the donor.

**1996**—Congress authorizes mailing organ and tissues donation information with income tax refunds (sent to approximately 70 million households).

**1998**—Plasmapheresis was introduced to enable kidney transplant in patients whose ABO blood group or antibodies are incompatible with the donor.

—First successful hand transplant performed in France.

—The Centers for Medicare and Medicaid Services issued its Hospital Conditions of Participation in Medicare and Medicaid programs requiring participating hospitals to refer all deaths and imminent deaths to the local organ procurement organization.

**1999**—Institute of Medicine Report released its report, *Organ Procurement and Transplantation*, with five recommendations. Among these were recommendations to: discontinue the use of waiting time in allocation of less severely ill liver patients; reaffirm the federal government's OPTN oversight role; establish independent review of the OPTN; and improve OPTN collection and availability to independent investigators for research or analysis.

—Organ Donor Leave Act was passed by Congress to allow federal employees to receive paid leave to serve as living organ or marrow donors.

**1999**—First hand transplant performed in the U.S.

### The 2000s

**2000**—Children's Health Act (PL 106-310): Amended the National Organ Transplant Act to require the OPTN to consider special issues concerning pediatric patients who should be considered in organ allocation.

**2001**—HHS Secretary Tommy G. Thompson launched his national Gift of Life Donation Initiative to increase organ, tissue, marrow, and blood donation.

—Number of living donors exceeds number of deceased donors for the first time in the U.S.

**2002**—Up-to-the-minute data on the number of people waiting for organ transplants in the United States are now available online through the OPTN.

—Department of Health and Human Services premieres its new documentary, *No Greater Love* at the Ronald Reagan Building, Washington, DC. This hour long film, narrated by Angela Lansbury and produced by Banyan Communications, depicts the power of transplantation and the critical need for more donors.

**2003**—No Greater Love won a national EMMY™ award for community service documentaries (See 2002).

—The Organ Donation Breakthrough Collaborative was launched by the U.S. Department of Health and Human Services to increase donation in the nation's largest hospitals by implementing an intensive and highly focused program to promote widespread use of best practices. In 2005, transplant centers joined the initiative with the goal of increasing the number of organs per donor. A revised version of the program continues today as the Donation and Transplantation Community of Practice.

—HHS Secretary Tommy G. Thompson designates April as National Donate Life Month.

**2004**—Organ Donation and Recovery Improvement Act (PL 108-216): expanded authorities of the National Organ Transplant Act to among other things, provide reimbursement of travel and subsistence expenses for living organ donors, and grants to states and public entities.

**2005**—First successful partial face transplant performed in France.

**2006**—Donate Life America launched its Donor Designation Collaborative to increase the total number of registered donors in the U.S. to 100 million.

—Institute of Medicine (IOM) released a new report, *Organ Donation: Opportunities for Action*. The IOM examined the ethical and societal implications of numerous strategies to increase deceased donation and considered several ethical issues regarding living donation, resulting in the presentation of seventeen recommendations for action.

**2007**—Charlie W. Norwood Living Organ Donation Act (PL 110-144): established that paired donation is not considered valuable consideration for purposes of Section 301 of the National Organ Transplant Act.

**2008**—Stephanie Tubbs Jones Gift of Life Medal Act (PL 110-113): establishes authority for the Department of Health and Human Services to issue a National Medal honoring organ donors.

**2009**—END THE WAIT! Campaign launched by the National Kidney Foundation to increase organ donation and eliminate the kidney waiting list.

**2010**—Health Resources and Services Administration (HRSA) recruited an expert panel to address circulatory death criteria.

**2011**—Advisory Committee on Organ Transplantation discussed a kidney policy update, identifying improvements in allocation policy.

**2012**—Organ Procurement and Transplantation Network (OPTN) approved a “National Share 15” policy and a “Regional Share 35” policy. Health Resources and Services Administration provides an additional \$500,000 in funding to the Scientific Registry of Transplant Recipients (SRTR) to conduct research of evidence-based approaches for geographic liver distribution.

**2013**—Health Resources and Services Administration provides \$1.6 million in funding to United Network for Organ Sharing to conduct a study evaluating donor potential in the United States.

## APPENDIX D

### FREQUENTLY ASKED QUESTIONS REGARDING ORGAN DONATION

- What is a Registry?

It is a secure database listing everyone who has given consent to become an organ donor.

- Why is it Important to join the Registry?

It is a way for others to know of your decision at the time of your death, and let your family know your wishes. It can provide timely information when needed.

- How do I join the Registry?

You can join the registry by consenting to become an organ donor when you get your drivers permit/license, visiting Donor Alliance, or going to Donate Life Colorado.

- Can I take my name off the Registry?

To remove your name from the registry you can either fill out the online form located on the registry website or send your request to be removed in writing to the Colorado Donor Registry at 720 South Colorado Boulevard, Suite 800-N, Denver, Co. 80246. You will be mailed a notification card, which you are asked to sign and return to confirm your request. Even though you are removed from the registry, your family will still be contacted by an organ donor coordinator and asked if they would like to make the decision at the time of your death.

- If I have chronic health issues can I still be a donor?

Health conditions do not automatically rule out donation--even those with cancer and Hepatitis C, or diabetes can donate life.

- What organs and tissues can be donated?

The heart, lungs, liver, kidneys, pancreas, lungs, and small intestines can be donated.

- Can organs be bought and sold?

It is a federal crime to buy and sell organs; violators can be fined up to \$50,000 and/or be imprisoned for a maximum of five years.

- Is there an age limit to be a donor? Is there an age limit to be a donor?

Due to ever changing criteria, everyone is considered a potential donor. No one is ruled out solely based on age; however age is considered depending on the specific organs that will be recovered.



- Does my religion support donation?

Nearly all major religions support the gift of life and see this as a charitable act.

- Will my body be disfigured by donation?

One can have an open casket funeral, and generally there is no noticeable difference in the appearance of the body.

- Is there any cost to my family?

The families of donors incur no financial burden when their loved ones choose to become an organ donor.

- Can I specify which organs to donate?

You may opt out of donating specific organs when registering online at [DonateLifeColorado.org](http://DonateLifeColorado.org) under “additional comments”.

Source: Midwest Transplant Network, 2013

## APPENDIX E

### TRANSPLANT CENTERS IN COLORADO

Porter Transplant Center  
2535 Downing Street, Suite 380  
Denver, CO 80210  
(303) 778-5797  
[www.porterhospital.org](http://www.porterhospital.org)

Children's Hospital Colorado  
13123 East 16<sup>th</sup> Avenue  
Aurora, CO 80045  
(720) 777- 1234  
[www.childrenscolorado.org](http://www.childrenscolorado.org)

Presbyterian/St. Luke's Medical Center  
1719 E. 19<sup>th</sup> Avenue  
Denver, CO 80218  
(303) 839-6000  
[www.uchealth.org/transplant](http://www.uchealth.org/transplant)

University of Colorado Hospital  
12605 E. 16<sup>th</sup> Avenue  
Aurora, CO 80045  
Attn: Transplant Center  
(720) 848-0000  
[www.uchealth.org/metrodenver/Pages/default.aspx](http://www.uchealth.org/metrodenver/Pages/default.aspx)

Donate Life Colorado, 2013

## APPENDIX F

### RELIGIOUS VIEWS REGARDING ORGAN DONATION

#### **AME & AME Zion (African Methodist Episcopal)**

Organ, tissue, and eye donation is viewed as an act of neighborly love and charity by these denominations. They encourage all members to support donation as a way of helping others.

#### **Amish**

The Amish will consent to transplantation if they believe it is for the well-being of the transplant recipient. John Hostetler, world renowned authority on Amish religion and Professor of Anthropology at Temple University in Philadelphia, says in his book, *Amish Society*, “The Amish believe that since God created the human body, it is God who heals. However, nothing in the Amish understanding of the Bible forbids them from using modern medical services, including surgery, hospitalization, dental work, anesthesia, blood transfusions or immunizations.” (p. 314-315).

#### **Assemblies of God**

The church has no official policy in regards to organ, tissue, and eye donation. The decision to donate is left up to the individual. Donation is highly supported by the denomination.

#### **Bahá’i**

The belief system of the Bahá’i faith adheres to 12 basic societal values, all of which support the concept of charitable acts and human kindness, and that all life is equally valued. The core principles: the unity of God, the unity of religion, and the unity of mankind support the concept of giving unselfishly.

#### **Baptist**

Organ, tissue, and eye donation is supported as an act of charity. The Baptists Church leaves the decision up to the individual. The nation’s largest Protestant denomination, the Southern Baptist Convention, adopted a resolution in 1988 encouraging physicians to request organ donation in appropriate circumstances and to “...encourage voluntarism regarding organ donation in the spirit of stewardship, compassion for the needs of others and alleviating suffering.”

#### **Brethren**

While no official position has been taken by the Brethren denominations, according to Pastor Mike Smith, there is a consensus among the National Fellowship of Grace Brethren that organ, tissue, and eye donation is a charitable act so long as it does not impede the life or hasten the death of the donor or does not come from an unborn child.

#### **Buddhism**

Buddhists believe that organ, tissue, and eye donation is a matter of individual conscience and place high value on acts of compassion. Reverend Gyomay Masao, President and Founder of the Buddhist Temple of Chicago says,

“We honor those people who donate their bodies and organs to the advancement of medical science and to saving lives.” The importance of letting loved ones know your wishes is stressed.

### **Catholicism**

Catholics view organ, tissue, and eye donation as an act of charity and love. Transplants are morally and ethically acceptable to the Vatican. According to Father Leroy Wickowski, Director of the Office of Health Affairs of the Archdiocese of Chicago, “We encourage donation as an act of charity. It is something good that can result from tragedy and a way for families to find comfort by helping others.” Pope John Paul II has stated, “The Catholic Church would promote the fact that there is a fraternal love so long as ethical principles are followed.” As well, Pope Benedict XVI told an interviewer he has been a card-carrying donor for years, saying “to donate one’s organs is an act of love...”

### **Christian Church (Disciples of Christ)**

The Christian Church encourages organ, tissue, and eye donation, stating that we were created for God’s glory and for sharing God’s love. A 1985 resolution, adopted by the General Assembly, encourages, “...members of the Christian Church (Disciples of Christ) to enroll as organ donors and prayerfully support those who have received an organ transplant.”

### **The Church of the Nazarene**

The Church of the Nazarene encourages its members who do not object personally to support donor/recipient anatomical organs through living wills and trusts. Further, they appeal for a morally and ethically fair distribution of organs to those qualified to receive them (Manual, Church of the Nazarene 1997-2001).

### **Christian Science**

The Church of Christ Scientist does not have a specific position regarding organ, tissue, and eye donation. According to the First Church of Christ Scientist in Boston, Christian Scientists normally rely on spiritual means of healing instead of medical. They are free; however, to choose whatever form of medical treatment they desire including a transplant. The question of organ, tissue, and eye donation is an individual decision.

### **Episcopal**

In 1982, the Episcopal Church passed a resolution recognizing the life-giving benefits of organ, blood, and tissue donation and encouraging all Christians to become organ, blood, and tissue donors “as part of their ministry to others in the name of Christ, who gave His life that we may have life in its fullness.”

### **Greek Orthodox**

According to Reverend Dr. Milton Efthimiou, Director of the Department of Church and Society for the Greek Orthodox Church of North and South America, “The Greek Orthodox Church is not opposed to organ, tissue, and eye donation as long as the organs and tissue in question are used to better human life, i.e., for the transplantation or for research that will lead to improvements in the treatment and prevention of disease.”

### **Gypsies**

Gypsies are a people of different ethnic groups without a formalized religion. They share common folk beliefs and tend to be opposed to organ, tissue, and eye donation. Their opposition is connected with their beliefs about the afterlife. Traditional belief contends that for one year after death, the soul retraces its steps. Thus, the body must remain intact because the soul maintains its physical shape.

## **Hinduism**

According to the Hindu Temple Society of North America, Hindus are not prohibited by religious law from donating their organs. This act is an individual's decision. H. L. Trivedi, in *Transplantation Proceedings*, stated, "Hindu mythology has stories in which the parts of the human body are used for the benefit of other humans and society. There is nothing in the Hindu religion indicating that parts of humans, dead or alive, cannot be used to alleviate the suffering of other humans."

## **Independent Conservative Evangelical**

Generally, Evangelicals have no opposition to organ, tissue, and eye donation. Each church is autonomous and leaves the decision to donate to the individual.

## **Islam**

The religion of Islam strongly believes in the principle of saving human lives. According to A. Sachedina in his *Transplantation Proceedings* (1990) article, "Islamic Views on Organ Transplantation," "...the majority of the Muslim scholars belonging to various schools of Islamic law have invoked the principle of priority of saving human life and have permitted the organ transplant as a necessity to procure that noble end."

## **Jehovah's Witnesses**

According to the Watch Tower Society, Jehovah's Witnesses believe donation is a matter of individual decision. Jehovah's Witnesses are often assumed to be opposed to donation because of their belief against blood transfusion. However, this merely means that all blood must be removed from the organs and tissues before being transplanted.

## **Judaism**

All four branches of Judaism (Orthodox, Conservative, Reform, and Reconstructionist) support and encourage donation. According to Orthodox Rabbi Moses Tendler, Chairman of the Biology Department of Yeshiva University in New York City and Chairman of the Bioethics Commission of the Rabbinical Council of America, "If one is in the position to donate an organ to save another's life, it's obligatory to do so, even if the donor never knows who the beneficiary will be. The basic principle of Jewish ethics--'the infinite worth of the human being'--also includes donation of corneas, since eyesight restoration is considered a life-saving operation." In 1991, the Rabbinical Council of America (Orthodox) approved organ donations as permissible, and even required, from brain-dead patients. The Reform movement looks upon the transplant program favorably, and Rabbi Richard Address, Director of the Union of America Hebrew Congregation Bio-Ethics Committee and Committee on Older Adults, states "Judaic Responsa materials provide a positive approach, and by and large the North American Reform Jewish community approves of transplantation."

## **Lutheran**

In 1984, the Lutheran Church in America passed a resolution stating that donation contributes to the well-being of humanity and can be "an expression of sacrificial love for a neighbor in need." They call on "members to consider donation organs and to make any necessary family and legal arrangements, including the use of a signed donor card."

## **Mennonite**

Mennonites have no formal position on donation, but are not opposed to it. They believe the decision to donate is up to the individual and/or their family.

## **Moravian**

The Moravian Church has made no statement addressing organ, tissue, and eye donation or transplantation. Robert E. Sawyer, President, Provincial Elders Conference, Moravian Church of America, Southern Province states, "There is nothing in our doctrine or policy that would prevent a Moravian pastor from assisting a family in making a decision to donate or not to donate an organ." It is, therefore, a matter of individual choice.

## **Mormon (Church of Jesus Christ of Latter-day Saints)**

The Church of Jesus Christ of Latter-day Saints believes that the decision to donate is an individual one made in conjunction with family, medical personnel, and prayer. They do not oppose donation. Jerry Cahill, Director of Public Affairs for the Mormon Church, says, "Mormons must individually weigh the advantages and disadvantages of transplantation and choose the one that will bring them peace and comfort. The Church does not interpose any objection to an individual decision in favor of organ, tissue, and eye donation."

## **Native American**

"God, Creator, Great Spirit. At the heart of American Indian spirituality is belief in an *Essence of Spirit: a Higher Power*, who is omniscient and immanent throughout the universe and who has created all that is seen and unseen.

All is Sacred, as All are Relatives. American Indian spirituality teaches that *Great Spirit* is imminent within all Creation and manifested and reflected in all aspects and elements of the created Earth and all its inhabitants: human, animal, fowl, plant life, the rocks, the waters, etc. Thus, we are all relatives as *Great Spirit* is manifest and reflected in us.

Autonomy of the Individual. Spirituality for a Native American is an individual choice and a family matter. There are no intermediaries between the individual and Creator. American Indian Spirituality encourages the seeker to find his or her own truth and form his or her own personal relationship with *Spirit* assisted by personal mentorship of an elder.

## **Pentecostal**

Pentecostals believe that the decision to donate should be left up to the individual.

## **Presbyterian**

Presbyterians encourage and support donation. They respect a person's right to make decision regarding their own body.

## **Protestant**

Protestants encourage and endorse organ, tissue, and eye donation. The Protestant faith (which includes many faiths) respects an individual's conscience and a person's right to make decisions regarding his or her own body. Reverend James W. Rassbach, Lutheran Board of Communication Services, Missouri-Synod, says "We accept and believe that our Lord Jesus Christ came to give life and give it in abundance. Organ, tissue, and eye donations enable more abundant life, alleviate pain and suffering, and are an expression of love in times of tragedy."

### **Seventh-day Adventist**

Donation and transplantation are strongly encouraged by Seventh-day Adventists. They have many transplant hospitals, including Loma Linda in California. Loma Linda specializes in pediatric heart transplantation.

### **Shinto**

In Shinto, the dead body is considered to be impure and dangerous, and thus quite powerful. “In folk belief context, injuring a dead body is a serious crime...,” according to E. Namihira in his article, “Shinto Concept Concerning the Dead Human Body.” “To this day it is difficult to obtain consent from bereaved families for organ, tissue, or eye donation or dissection for medical education or pathological anatomy...the Japanese regards them all in the sense of injuring a dead body. Families are often concerned that they not injure the itai--the relationship between the dead person and the bereaved people.”

### **Society of Friends (Quakers)**

Organ, tissue, and eye donation is believed to be an individual decision. The Society of Friends does not have an official position on donation. Officials for the Quakers do not oppose organ, tissue, and eye donation and transplantation.

### **Unitarian Universalist**

Organ, tissue, and eye donation is widely supported by Unitarian Universalist. They view it as an act of love and selfless giving.

### **United Church of Christ**

Reverend Jay Lintner, Director, Washington Office of the United Church of Christ Office for Church in Society, states, “United Church of Christ people, churches and agencies are extremely and overwhelmingly supportive of organ sharing. The General Synod has never spoken to this issue because, in general, the Synod speaks on more controversial issues, and there is no controversy about organ sharing, just as there is no controversy about blood donation in the denomination. Any organized effort to get the General Synod delegates or individual churches to sign organ, tissue, and eye donation cards would meet with generally positive responses.”

### **United Methodist**

The United Methodist Church issued a policy statement in regards to organ, tissue, and eye donation. In it, they state “The United Methodist Church recognizes the life-giving benefits of organ, tissue, and eye donation, and thereby encourages all Christians to become organ, tissue, and eye donors by signing and carrying cards of driver’s licenses, attesting to their commitment of such organs upon their death, to those in need, as a part of their ministry to others in the name of Christ, who gave His life that we might have life in its fullness.” A 1992 resolution states, “Donation is to be encouraged, assuming appropriate safeguards against hastening death and determination of death by reliable criteria.” The resolution further states, “Pastoral-care persons should be willing to explore these options as a normal part of conversation with patients and their families.”

### **Wesleyan Church**

The Wesleyan Church supports donation as a way of helping others. They believe that God’s “ability to resurrect us is not dependent on whether or not all our parts were connected at death.” They also support research and have noted “one of the ways that a Christian can do good is to request that their body be donated to a medical school for use in teaching.”

**Wiccan**

There is a prevalent belief in the Craft that the soul not only transcends the body, but also immanently exists in body's parts. Therefore, it is likely that a Wiccan faced with receiving a transplant would undergo specific rites to purify their body prior to surgery, to thank the donor, and to focus on integrating an organ from another into themselves. The decision to donate organs is an individual's choice.



APPENDIX G

PILOT STUDY SURVEY

**Students Voices: Organ Transplantation and Donation**

**WE WANT YOUR OPINION: THIS IS NOT A TEST AND IT DOES NOT AFFECT  
YOUR GRADE**

**Definitions to help you respond**

**Organ Transplantation:** When a person’s vital organs, such as kidneys, heart, liver, or lungs, fail to work properly, the person may die. A healthy replacement organ allows some people to live. The surgical operation in which a diseased organ is replaced with a healthy one is a transplant.

**Organ Donation:** The act of a person (organ donor) giving an organ to another person (recipient) in need of a healthy organ is an organ donation. For some organs, this donation can be given while the person is alive—in other cases, the donation is made at death. Organs = kidney, liver, heart, lung, and pancreas.

**Organ Donor Card:** A law permits people to decide and designate their wishes to be an organ donor. A person who wishes to be a donor signs and carries a card. In Colorado one’s driver’s license is the donor card when it has a heart in the lower right corner.

School: \_\_\_\_\_

Class: \_\_\_\_\_

Student I.D: \_\_\_\_\_

Date: \_\_\_\_\_

## Organ Transplantation and Donation

### Interesting Facts about Transplantation and Donation---Do you know?

Circle only one response for each item.

1. Transplant survival rates today are very high.  
True                      False                      Don't Know
2. Almost one half of the persons waiting for organ transplants in the United States are from minority groups.  
True                      False                      Don't Know
3. African-Americans wait longer for transplants than Caucasians/whites.  
True                      False                      Don't Know
4. Asian-Americans wait longer for transplants than Caucasians/whites.  
True                      False                      Don't Know
5. Latinos wait longer for transplants than Caucasians/whites.  
True                      False                      Don't Know
6. Blood type doesn't make any difference for getting a donated organ.  
True                      False                      Don't Know
7. Most organs received by minorities are donated by Caucasians donors.  
True                      False                      Don't Know
8. People wouldn't need transplants if they took better care of themselves.  
True                      False                      Don't Know

9. More people die from automobile accidents and gun -shot wounds than from heart disease each year.
- True                      False                      Don't Know
10. A recipient can receive an organ from a living donor.
- True                      False                      Don't Know
11. A national computer system matches and distributes donated organs to the persons who are the sickest and to those who have been waiting the longest.
- True                      False                      Don't Know
12. Transplant recipients can live more than 10 years after a transplant operation.
- True                      False                      Don't Know
13. The recipient's chance of surviving a transplant operation today is pretty low.
- True                      False                      Don't Know
14. Sometimes, organs can be sold for money in the United States.
- True                      False                      Don't Know
15. Rich or famous people can receive organs before the people with the most need.
- True                      False                      Don't Know
16. A transplant operation has less than a 50/50 chance of allowing the recipient to return to normal activities.
- True                      False                      Don't Know

**Personal Experience:**

17. Where have you heard about organ transplantation?

**Mark an X in all boxes that apply where you have heard about organ transplantation- refer to page one for definitions.**

Religious Organizations	Family	Friends	Internet	Radio	TV	School	Other

18. Where have you heard about organ donation?

**Mark an X in all boxes that apply where you have heard about organ donation- refer to page one for definitions.**

Religious Organizations	Family	Friends	Internet	Radio	TV	School	Other

For the following questions, **circle** the appropriate responses.

19. **Who do you know who has received an organ transplant?**

No one (skip to question 20)    Friend                      Relative                      Other

Circle a response for b & c for one person you know

(b) Is this person who received an organ transplant:

Younger than you                      About your age                      Older than you

(c) Is this person similar in ethnic/racial background to you:

Similar                      Different                      I don't know

20. **Do you know someone who is or has been on the waiting list for an organ transplant?**

No one (skip to question 21)    Friend                      Relative                      Other

Circle a response for b & c for one person you know

(b) Is this person who is on the waiting list:

Younger than you                      About your age                      Older than you

(c) Is this person similar in ethnic/racial background to you:

Similar                      Different                      I don't know

21. **Do you know someone who is a living donor?**

No one (skip to questions 22)    Friend                      Relative                      Other

Circle a response for b & c for one person you know

(b) Is this living donor:

Younger than you                      About your age                      Older than you

(c) Is this living donor similar in ethnic/racial background to you:

Similar                      Different                      I don't know

22. **Do you know someone who donated their organs after death?**

No one (skip to question 23)    Friend                      Relative                      Other

Circle a response for b & c for one person you know

(b) Is this person who donated their organs after death:

Younger than you                      About your age                      Older than you

(c) Is this person who donated similar in ethnic/racial background as you:

Similar                      Different                      I don't know

23. Have you ever talked about organ donation with your family?

Yes                      No                      Unsure

24. Do you know what your family thinks about organ donation?

Yes                      No                      Unsure

**Your Opinions about Transplantation and Donation:**

25. I would be willing to be an organ recipient? (Circle one that comes closest to your feelings)

Strongly agree    Agree    I don't know    Disagree                      Strongly disagree

From the list below circle all reasons that influence your opinion:

- I am afraid of the surgery or procedure
- It is against my religion
- I don't want to think about dying
- I am worried about what my family would do/think
- I am worried that the procedure won't be successful

26. I would be willing to be an organ donor? (Circle one that comes closest to your feelings)

Strongly agree                      Agree    I don't know    Disagree                      Strongly disagree

a) From the list below circle all reasons that influence your opinion:

- I am afraid of the surgery or procedure
- I worry about how my body would look, even if the organs are removed (taken out) after death.
- I worry that, if I donate, my organs would only go to rich people.
- I worry that doctors may not try hard to make me well if I carry a card saying that I want to be an organ donor.
- I think the body should remain whole after death.
- I would want to save a life if I could.

27. Would you be willing to make a living donation of one of your kidneys, lungs, or a part of your liver to someone in your family if he/she needed a transplant?

Yes                      No                      Unsure

**About Yourself/Who are you? Circle the appropriate responses of fill in the blank.**

28. What is your:

Age:    13      14      15      16      17      18

Gender: M      F

Grade: Freshman      Sophomore      Junior      Senior

Grade Point Average at end of last term \_\_\_\_\_

Religion \_\_\_\_\_

29. What is your ethnic background (Circle each one that applies)

African-American

Hispanic

Alaska Native

Asian-American

American Indian

Caucasian/white

Other \_\_\_\_\_

30. What language do you usually speak at home?

English

Spanish

Other

31. What was the highest level of education completed by each parent?

**Father:** Grade school Middle/Jr. high High school College degree  
Graduate degree Don't know

**Mother:** Grade school Middle/Jr. high High school College degree  
Graduate degree Don't know

32. Are you planning on attending college or other school after completing high school?

Yes No Unsure

33. Do you have your: Permit Driver's License Neither

If you have a permit or license, does it have a red heart on it indicating you are a donor?

Yes No Unsure

**THANK YOU FOR SHARING YOUR OPINIONS.**



APPENDIX H

PRE-SURVEY

**Students Voices: Organ Transplantation and Donation**

**WE WANT YOUR OPINION: THIS IS NOT A TEST AND IT DOES NOT AFFECT  
YOUR GRADE**

**This is a research survey – All information will be kept CONFIDENTIAL**

**Definitions to help you respond**

**Organ Transplantation**: When a person’s vital solid organs, such as kidneys, heart, liver, or lungs, fail to work properly, the person may die. A healthy replacement organ allows some people to live. The surgical operation in which a diseased solid organ is replaced with a healthy one is a transplant.

**Organ Donation**: The act of a person (organ donor) giving a solid organ to another person (recipient) in need of a healthy solid organ is an organ donation. For some organs, this donation can be given while the person is alive—in other cases, the donation is made at death. Solid organs = kidney, liver, heart, lung, and pancreas.

**Organ Donor Card**: A law permits people to decide and designate their wishes to be an organ donor. A person who wishes to be a donor signs and carries a card. In Colorado, one’s driver’s license is the card with a designating heart in the lower right corner.

Grade: \_\_\_\_\_

Student ID: \_\_\_\_\_

Class Period: \_\_\_\_\_

Date: \_\_\_\_\_

## Organ Transplantation and Donation

**Circle only one response for each item number. It is important that your response indicates what you know. Rather than guessing, 'Don't know' should be your response when you do not know.**

1. Transplant survival rates today are very high.

True                      False                      Don't Know

2. Almost one half of the persons waiting for organ transplants in the United States are from minority groups.

True                      False                      Don't Know

3. African-Americans wait longer for kidney transplants than Caucasians/whites.

True                      False                      Don't Know

4. Asian-Americans wait longer for kidney transplants than Caucasians/whites.

True                      False                      Don't Know

5. Latinos have a chronic liver disease rate that is twice that of Caucasians/whites.

True                      False                      Don't Know

6. Blood type doesn't make any difference for getting a donated organ.

True                      False                      Don't Know

7. Most organs received by minorities are donated by Caucasians.

True                      False                      Don't Know

8. People wouldn't need transplants if they took better care of themselves.

True                      False                      Don't Know

9. More people die from automobile accidents and gunshot wounds than from heart disease each year.
- True                      False                      Don't Know
10. A recipient can receive an organ from a living donor.
- True                      False                      Don't Know
11. A recipient's chance of surviving a transplant operation today is pretty low.
- True                      False                      Don't Know
12. Transplant recipients can live more than 10 years after a transplant operation.
- True                      False                      Don't Know
13. A national computer system matches and distributes donated organs to the persons who are the sickest and to those who have been waiting the longest.
- True                      False                      Don't Know
14. Sometimes, organs can be sold on the black market for money in the United States.
- True                      False                      Don't Know
15. Rich or famous people can receive organs before the people with the most need.
- True                      False                      Don't Know
16. A transplant operation has less than a 50/50 chance of allowing the recipient to return to normal activities.
- True                      False                      Don't Know

**Personal Experience:**

The following questions refer to individual events regarding your source of knowledge and knowing someone who may have influenced you.

17. Where or from who have you heard about organ transplantation/donation?

**Circle YES or NO for each of the sources that applies where you have heard about organ transplantation/donation--Refer to page one for definitions.**

Religious related Organization (e.g., Church, youth group, funerals/wakes, etc.)	Yes	No
Family	Yes	No
Friends	Yes	No
School	Yes	No
News Media (TV, radio, papers, public service announcement)	Yes	No
Entertainment (TV programs, movies, concerts)	Yes	No
Social Media (Facebook, Instagram)	Yes	No
Internet (Wikipedia, websites, donation sites, YouTube)	Yes	No
Other (specify) _____	Yes	

**For the following questions, X the appropriate responses.**

18. Do you know someone who has received an organ transplant?

No one (skip to 19)  Friend  Relative/Family  Other

**(X for b & c for one person you know if you indicated X for Friend, Relative/Family, or Other above in 18)**

(b) Is this person who received an organ transplant:

Younger than you  About your age  Older than you

(c) Is this person similar in ethnic/racial background to you:

Similar  Different  I don't know

19. Do you know someone who is or has been on the waiting list for an organ transplant?

No one (skip to 20)  Friend  Relative/Family  Other

**(X for b & c for one person you know if you indicated X for Friend, Relative/Family, or Other above in 19)**

(b) Is this person who is on the waiting list:

Younger than you  About your age  Older than you

(c) Is this person similar in ethnic/racial background to you:

Similar  Different  I don't know

20. Do you know someone who is a living donor of a solid organ?

No one (skip to 21)       Friend       Relative/Family       Other

**(X for b & c for one person you know if you indicated X for Friend, Relative/Family, or Other above in 20).**

(b) Is this living donor:

Younger than you       About your age       Older than you

(c) Is this living donor similar in ethnic/racial background to you:

Similar       Different       I don't know

21. Do you know someone who donated their organs after death?

No one (skip to 22)       Friend       Relative/Family       Other

**(X for b & c for one person you know if you indicated X for Friend, Relative/Family, or Other above in 21).**

(b) Is this person who donated their organs after death:

Younger than you       About your age       Older than you

(c) Is this person who donated similar in ethnic/racial background to you:

Similar       Different       I don't know

**Your Willingness to Consent:**

22. Many reasons influence willingness to consent to being an organ donor. (**Circle your willingness from 1 to 5 for each item listed below**)

How willing would I be to consent to be an organ donor if:

	Not Very Willing			Very Willing	
- I could save a life	1	2	3	4	5
- It's an act of kindness and altruism	1	2	3	4	5
- It's against my religion	1	2	3	4	5
- I am afraid of the surgery or procedure	1	2	3	4	5
- I think about how my body would look after donation	1	2	3	4	5
- I think my organs would only go to rich people	1	2	3	4	5
- I think doctors may not try as hard to make me well if I carry a card saying that I want to be an organ donor	1	2	3	4	5
- I think my body should remain whole after donation	1	2	3	4	5
- I could save a family member	1	2	3	4	5

23. If asked today, would you consent to be an organ donor?

Yes                      No                      Unsure

**About Yourself/Who are you? (Circle or write in the appropriate response for each).**

What is your:

24. Age: 13 14 15 16 17 18 19

Gender: M F

Grade: Freshman Sophomore Junior Senior

Grade Point Average at end of last term\_\_\_\_\_

Religion: Catholic Jewish Mormon Non-Denominational Other N/A

What languages do you usually speak at home? English Spanish Bilingual Other,  
list\_\_\_\_

25. What is your ethnic background (**Circle ALL that apply**)

Black Hispanic

Hawaiian Pacific Asian

American Indian/Alaskan Native White

Other (specify) \_\_\_\_\_

26. What was the highest level of education completed by **each** parent? (**Circle highest level for EACH parent**)

**Father:**

Not in home  
Grade school  
Middle/Jr. high  
High school  
Tech school/Professional Cert.  
Some college  
College degree  
Graduate degree  
Don't know

**Mother:**

Not in home  
Grade school  
Middle/Jr. high  
High school  
Tech school/Professional Cert.  
Some college  
College degree  
Graduate degree  
Don't know



27. Do you have your Driver's (**Circle one**):  
Permit    License    Neither (skip to # 31)
28. If you have your permit/license, does it have a red heart on it indicating you are a donor?  
(**Circle one response**)  
Yes                  No                  Unsure
29. Did the Department of Motor Vehicle personnel directly ask you if you wanted to be an organ donor when you got your permit/license? (**Circle one**):  
Yes                  No                  Don't remember
30. Did the Department of Motor Vehicle personnel directly ask your parent if you wanted to be an organ donor? (**Circle one**):  
Yes                  No                  Don't remember
31. Please share here any thoughts you have regarding organ donation:

**THANK YOU FOR COMPLETING THIS SURVEY**

APPENDIX I

POST-SURVEY

**Students Voices: Organ Transplantation and Donation**

**WE WANT YOUR OPINION: THIS IS NOT A TEST AND IT DOES NOT AFFECT  
YOUR GRADE**

**This is a research survey – All information will be kept CONFIDENTIAL**

**Definitions to help you respond**

**Organ Transplantation**: When a person's vital solid organs, such as kidneys, heart, liver, or lungs, fail to work properly, the person may die. A healthy replacement organ allows some people to live. The surgical operation in which a diseased solid organ is replaced with a healthy one is a transplant.

**Organ Donation**: The act of a person (organ donor) giving a solid organ to another person (recipient) in need of a healthy solid organ is an organ donation. For some organs, this donation can be given while the person is alive—in other cases, the donation is made at death. Solid organs = kidney, liver, heart, lung, and pancreas.

**Organ Donor Card**: A law permits people to decide and designate their wishes to be an organ donor. A person who wishes to be a donor signs and carries a card. In Colorado one's driver's license is the card with a designating heart in the lower right corner.

Grade: \_\_\_\_\_

Student ID: \_\_\_\_\_

Class Period: \_\_\_\_\_

Date: \_\_\_\_\_

## Organ Transplantation and Donation

**Circle only one response for each item number. It is important that your response indicates what you know. Rather than guessing, 'Don't know' should be your response when you do not know.**

1. Transplant survival rates today are very high.

True                      False                      Don't Know

2. Almost one half of the persons waiting for organ transplants in the United States are from minority groups.

True                      False                      Don't Know

3. African-Americans wait longer for kidney transplants than Caucasians/whites.

True                      False                      Don't Know

4. Asian-Americans wait longer for kidney transplants than Caucasians/whites.

True                      False                      Don't Know

5. Latinos have a chronic liver disease rate that is twice that of Caucasians/whites.

True                      False                      Don't Know

6. Blood type doesn't make any difference for getting a donated organ.

True                      False                      Don't Know

7. Most organs received by minorities are donated by Caucasians.

True                      False                      Don't Know

8. People wouldn't need transplants if they took better care of themselves.

True                      False                      Don't Know

9. More people die from automobile accidents and gunshot wounds than from heart disease each year.
- True                      False                      Don't Know
10. A recipient can receive an organ from a living donor.
- True                      False                      Don't Know
11. A recipient's chance of surviving a transplant operation today is pretty low.
- True                      False                      Don't Know
12. Transplant recipients can live more than 10 years after a transplant operation.
- True                      False                      Don't Know
13. A national computer system matches and distributes donated organs to the persons who are the sickest and to those who have been waiting the longest.
- True                      False                      Don't Know
14. Sometimes, organs can be sold on the black market for money in the United States.
- True                      False                      Don't Know
15. Rich or famous people can receive organs before the people with the most need.
- True                      False                      Don't Know
16. A transplant operation has less than a 50/50 chance of allowing the recipient to return to normal activities.
- True                      False                      Don't Know

**Personal Experience:**

The following questions refer to individual events regarding your source of knowledge and knowing someone who may have influenced you.

17. Where or from who have you heard about organ transplantation/donation?

**Circle YES or NO for each of the sources that applies where you have heard about organ transplantation/donation--Refer to page one for definitions.**

Religious related Organization (e.g., Church, youth group, Funerals/wakes etc.)	Yes	No
Family	Yes	No
Friends	Yes	No
School	Yes	No
News Media (TV, radio, papers, public service announcement)	Yes	No
Entertainment (TV programs, movies, concerts)	Yes	No
Social Media (Facebook, Instagram)	Yes	No
Internet (Wikipedia, websites, donation sites, YouTube)	Yes	No
Other (specify) _____	Yes	

**For the following questions, X the appropriate responses.**

18. Do you know someone who has received an organ transplant?

No one (skip to 19)  Friend  Relative/Family  Other

**(X a response for b & c for one person you know if you indicated X for Friend, Relative/Family, or Other above in 18)**

(b) Is this person who received an organ transplant:

Younger than you  About your age  Older than you

(c) Is this person similar in ethnic/racial background to you:

Similar  Different  I don't know

19. Do you know someone who is or has been on the waiting list for an organ transplant?

No one (skip to 20)  Friend  Relative/Family  Other

**(X a response for b & c for one person you know if you indicated X for Friend, Relative/Family, or Other above in 19)**

(b) Is this person who is on the waiting list:

Younger than you  About your age  Older than you

(c) Is this person similar in ethnic/racial background to you:

Similar  Different  I don't know

20. Do you know someone who is a living donor of a solid organ?

No one (skip to 21)       Friend       Relative/Family       Other

**(X a response for b & c for one person you know if you indicated X for Friend, Relative/Family, or Other above in 20).**

(b) Is this living donor:

Younger than you       About your age       Older than you

(c) Is this living donor similar in ethnic/racial background to you:

Similar       Different       I don't know

21. Do you know someone who donated their organs after death?

No one (skip to 22)       Friend       Relative/Family       Other

**(X a response for b & c for one person you know if you indicated X for Friend, Relative/Family, or Other above in 21).**

(b) Is this person who donated their organs after death:

Younger than you       About your age       Older than you

(c) Is this person who donated similar in ethnic/racial background to you:

Similar       Different       I don't know

**Your Willingness to Consent:**

22. Many reasons influence willingness to consent to being an organ donor. (**Circle your willingness from 1 to 5 for each item listed below**)

How willing would I be to consent to be an organ donor if:

	Not Very Willing			Very Willing	
- I could save a life	1	2	3	4	5
-It's an act of kindness and altruism	1	2	3	4	5
-It's against my religion	1	2	3	4	5
-I am afraid of the surgery or procedure	1	2	3	4	5
-I think about how my body would look after donation	1	2	3	4	5
-I think my organs would only go to rich people	1	2	3	4	5
-I think doctors may not try as hard to make me well if I carry a card saying that I want to be an organ donor	1	2	3	4	5
-I think my body should remain whole after donation	1	2	3	4	5
-I could save a family member	1	2	3	4	5

23. If asked today, would you consent to be an organ donor?

Yes                      No                      Unsure



24. Do you have your Driver's... **(Circle one):** Permit License Neither (skip to #28)

a) I got my permit or license after February 1, 2015.

Yes

No

25. If you have your driver's permit/license, does it have a red heart on it indicating you are a donor? **(Circle one response):**

Yes

No

Unsure

26. Did the Department of Motor Vehicle personnel directly ask you if you wanted to be an organ donor? **(Circle one):**

Yes

No

Don't Remember

27. Did the Department of Motor Vehicle directly ask your parent if you wanted to be an organ donor? **(Circle one):**

Yes

No

Don't Remember

28. Please share here any thoughts you have regarding organ donation:

**THANK YOU FOR COMPLETING THIS SURVEY**

**APPENDIX J**

**PARENTAL CONSENT**

**Dear Parent / Guardian,**

The Physical Education Department is committed to a comprehensive health education program as part of each student’s education. The health education program emphasizes skills and knowledge necessary for students to understand and appreciate the functioning and proper care of the human body so they can make healthful choices now and in the future. Students are presented with information regarding complex social, physical and mental health problems which will be encountered in society. \_\_\_\_\_ requires one semester of health for all students attending \_\_\_\_\_.

Class topics include:

stress management, first aid, adult CPR, infant/child CPR, sexuality, substance education, nutrition and fitness.

Instructional materials used for the Health course are available for inspection by the public during school hours. Should a parent wish to exempt their student from part of the course, please indicate below. A meeting would then be scheduled between the parent and instructor to formulate an alternative educational assignment.

This form must be signed and returned by ALL students enrolled in Health at \_\_\_\_\_ High School.

Please fill out the bottom of this form and return with your son / daughter to me at \_\_\_\_\_. Should you have any questions pertaining to health education please feel free to contact -

\_\_\_\_\_

Physical Education Department

I, \_\_\_\_\_ give my permission for my son/daughter

Parents Name

\_\_\_\_\_ to participate in health class      Students Name

Parents Signature: \_\_\_\_\_ Date: \_\_\_\_\_

APPENDIX K



NOTICE OF APPROVAL FOR HUMAN RESEARCH

**DATE:** October 26, 2014  
**TO:** Buchan, Victoria  
Robinson, Dan, 1588 School of Education, Hodgson, Margie, 1588 School of Education  
**FROM:** Swiss, Evelyn, Coordinator, CSU IRB 2  
Organ Donation and the Teenage Perspective-Factors to Consider Regarding Consent. (Proposal title). Student Voices:  
**PROTOCOL TITLE:** Organ Transplantation and Donation. (Protocol title).  
**FUNDING SOURCE:** NONE  
**PROTOCOL NUMBER:** 13-4736H  
**APPROVAL PERIOD:** Approval Date: October 02, 2014 Expiration Date: January 29, 2015

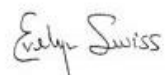
The CSU Institutional Review Board (IRB) for the protection of human subjects has reviewed the protocol entitled: Organ Donation and the Teenage Perspective-Factors to Consider Regarding Consent. (Proposal title). Student Voices: Organ Transplantation and Donation. (Protocol title). The project has been approved for the procedures and subjects described in the protocol. This protocol must be reviewed for renewal on a yearly basis for as long as the research remains active. Should the protocol not be renewed before expiration, all activities must cease until the protocol has been re-reviewed.

If approval did not accompany a proposal when it was submitted to a sponsor, it is the PI's responsibility to provide the sponsor with the approval notice.

This approval is issued under Colorado State University's Federal Wide Assurance 00000647 with the Office for Human Research Protections (OHRP). If you have any questions regarding your obligations under CSU's Assurance, please do not hesitate to contact us.

Please direct any questions about the IRB's actions on this project to: IRB Office - (970) 491-1553;  
[RICRO IRB@mail.Colostate.edu](mailto:RICRO_IRB@mail.Colostate.edu)  
Evelyn Swiss, IRB Coordinator - (970) 491-1381; [Evelyn.Swiss@Colostate.edu](mailto:Evelyn.Swiss@Colostate.edu)

Swiss, Evelyn



Swiss, Evelyn

Amendment is approved to: 1. Update the text of the pre and post survey instruments; 2. Update the sequence in which the questions are asked; 3. Update the numbering of the surveys; 4. Delete the OD Class questions; and 5. Change the curriculum (to include scenarios). No change in risk.

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**Approval Period:** October 02, 2014 through January 29, 2015

**Review Type:** EXPEDITED

**IRB Number:** 00000202

## APPENDIX L

### CURRICULUM

#### Curriculum-Background Information Regarding Organ Donation

1. Definitions: Recipient--the one who receives the organ. A recipient can get an organ from a living donor or a deceased donor and a recipient can live for more than 10 years after a transplant. Donor--the one that gives the organ.
2. A recipient has a better than 50% chance of returning to normal activities after the operations.
3. There are two (2) ways to indicate you want to be an organ donor:
  - DMV (Department of Motor Vehicle)
  - State Registry (Donate Life Colorado)
4. A national computer system matches and helps distribute organs across the country.
5. Approximately 120,000 people, nationally, are waiting for a transplant.
6. Most organs are donated by Caucasians.
7. Almost half of the people on the United States wait list are minorities and all minorities wait longer for organs than Caucasians.
8. Approximately 250 people are added to the waiting list every month (~8 a day).
9. 18 people per day (6,570 per year) die due to a lack of available organs.
10. Today transplant survival rates are very high.
11. Factors that contribute to a successful donation include a match of: Age, Blood Type, Size of Organ, and Distance between Donor and Recipient.
12. Myths regarding organ donation:
  - Some people believe organs can be bought/sold.
  - Some people believe only the rich/famous get organs.

## Scenarios (Groups)

**Instructions: Break into small groups (3-5) and discuss the following scenarios.**

1. Latinos have a chronic liver disease rate that is twice that of Caucasians/whites:  
  
-Who should be willing to be an organ donor, a single Hispanic woman with two young children **or** a Caucasian businessman who is ready to retire? Why?
  
2. Even people who take good care of themselves by eating healthy, exercising, and not smoking may need an organ transplant.  
  
-Who should get a healthy organ (transplant), someone who takes good care of themselves **or** someone who smokes cigarettes and drinks alcohol on a regular basis? Why?
  
3. Heart disease is one of the leading causes of death each year, more people die from heart disease than from car accidents and the use of weapons.  
  
-Who should be willing to be an organ donor, a middle aged man of 55 who smoked for 20 years and is 30 pounds overweight **or** an active college student who is healthy? Why?
  
4. Some people believe that the rich and/or famous get organs before the general public. Kevin, a three-time scoring champion and recent Most Valuable Player of the National Basketball Association who is 29, has recently been diagnosed with a pancreatic disorder and placed on a waiting list for an organ transplant. Jason, 31, a security guard, has a similar pancreatic disorder and has been on the waiting list for three years. An organ procurement organization has just identified a match for either or Kevin and Jason, who are equally ill.  
  
-Who do you think will most probably receive the organ? Why?

5. People can be on the wait list for an organ for years.

-Some believe that prisoners should be required to be organ donors to repay society for their crimes. Do you agree or disagree? Why?

6. People have various opinions about organ donation.

-Have you discussed your wishes regarding organ donation with your family?

## APPENDIX M

### STATISTICS OF ORGAN DONATION

#### **Local data:**

In Colorado and Wyoming, 2,438 people are currently waiting for an organ transplant.

Of those, 1,719 are waiting for a kidney—the organ most in need (71%)—and 625 are waiting for a liver (26%)

4 percent of current transplant candidates in Colorado have been on the waiting list for five years or more. Forty-six of those waiting for an organ transplant are between 50-64 years.

Colorado has one of the nation's highest-performing state donor registries with more than 67% of driver's license/ID card applicants registering as organ and tissue donors (as of 2013 end).

#### **National Stats:**

In 2014 slightly more than 121,000 people, nationally are waiting for transplants.

Every 10 minutes another name is added to the national transplant waitlist. On average of 245 people are added to the waitlist each month.

One organ donor can save up to eight lives through organ donation and more than 100 lives through tissue donation.

Every year, approximately 500,000 Americans are saved through organ and tissue donation.

Of those waiting, 15,781 (14%) need a liver transplant and 95,061 patients (81%) are in need of a kidney.

More than 6,000 living donations occur each year.

One in four donors is not biologically related to the recipient.

Source: Donate Life Colorado, 2014



## APPENDIX N

### RESOURCES FOR ORGAN DONATION

#### Local Organizations:

The Department of Motor Vehicle

Other Donor Registries

Health Department

Local Hospitals

Colorado Medical Society

Local Transplant Centers

#### National Organizations:

American Liver Foundation

American Medical Association

American Transplant Foundation

Children's Organ Transplant Association

Donate Life

Donor Alliance

Minority Donor Awareness Society

National Council on Minority Education in Transplant

National Foundation for Transplants

National Kidney Foundation

The Office of Minority Health

United Network for Organ Sharing

## APPENDIX O

### RESOURCES FOR RESEARCH AND WILLED BODY PROGRAMS AND STUDIES

Biogift  
17819 NE Riverside Pkwy Suite C  
Portland, OR 97230  
866-670-1799

Cleveland Chiropractic College  
913-234-0600

Cytonet  
1-919-354-3161

Harvard Medical School Anatomical Gift Program  
260 Longwood Avenue  
Boston, MA 02115  
617-432-1735

Institute for Plastination  
Im Bosseldorn 17  
69126 Heidelberg, Germany  
+49 6221 33 11 50

International Institute for the Advancement of Medicine (IIAM)  
888-496-7033

Kansas City University of Medical & Biosciences  
Kansas City, MO  
816-283-2242

Kansas University School of Medicine  
Department of Anatomy and Cell Biology  
Kansas City, KS 66160  
913-588-2735

LifeQuest Anatomical  
659 East Allen Street  
Allentown, PA 18109  
866-799-2300

Michigan State University  
939 Fee Road East 206  
East Lansing, MI 48824  
517-353-5398

National Development and Research Institutes, Inc. (NDRI)  
800-222-6374

Science Care  
21410 North 19<sup>th</sup> Avenue Suite 126  
Phoenix, AZ 85027  
800-417-3747

Stanford University School of Medicine  
269 Campus Drive  
Stanford, CA 94305-5140  
650-723-2404

University of California, Los Angeles  
David Geffen School of Medicine  
924 Westwood Blvd., Suite 335  
Los Angeles, CA 90095-7340  
310-794-0472

University of Central Florida  
6850 Lake Nona Blvd.  
Orlando, FL 32827  
407-266-1142

University of Colorado School of Medicine  
State Anatomical Board  
13070 E. 19th Avenue  
Aurora, CO 80045  
303-724-2410

University of Puerto Rico  
School of Medicine  
G.P.O. Box 5067  
San Juan, Puerto Rico 00936

UT Southwestern Medical Center  
5323 Harry Hines Blvd.  
Dallas, TX 75390-9143  
214-648-2221

University of Tennessee  
855 Monroe Avenue  
Memphis, TN 38163  
901-448-5965

University of Utah  
College of Medicine  
2C 110 Medical Center  
Salt Lake City, UT 84132  
801-581-6728

Xenotech  
913-473-3287

## APPENDIX P

### DONATION WEBSITES

- American Transplant Foundation: [americantransplantfoundation.org](http://americantransplantfoundation.org)
- American Society of Multicultural Health and Transplant Professionals: [asmhpt.org](http://asmhpt.org)
- Department of Health and Human Services: [organdonor.gov](http://organdonor.gov)
- Donate Life America: [donatelifeamerica.net](http://donatelifeamerica.net)
- Eye Bank Association of America: [restoresight.org](http://restoresight.org)
- Gift of Life: [giftdonor.org](http://giftdonor.org)
- Living Donors Online: [livingdonorsonline.org](http://livingdonorsonline.org)
- Midwest Transplant Network: [mwtn.org](http://mwtn.org)
- Minority Donor Awareness Society (MDAS)
- National Foundation for Transplants: [transplants.org](http://transplants.org)
- National Kidney Foundation: [kidney.org](http://kidney.org)
- National Kidney Foundation: [livingdonors.org](http://livingdonors.org)
- The National Minority Organ and Tissue Transplant Education Program: [nationalmottetp.org](http://nationalmottetp.org)
- The Office of Minority Health: [minorityhealth.hhs.gov](http://minorityhealth.hhs.gov)
- The Organ Procurement and Transplantation Network: [optn.transplant.hrsa.gov](http://optn.transplant.hrsa.gov)
- Organ Transplant Support Inc.: [otsfriends.org](http://otsfriends.org)
- Polycystic Kidney Disease: [pkdcure.org](http://pkdcure.org)
- United Network for Organ Sharing: [unos.org](http://unos.org)
- UNOS: [transplantliving.org](http://transplantliving.org)

## APPENDIX Q

### PRE-SURVEY CODING

#### **Organ Transplantation and Donation:**

Item 1: 0 = missing (left blank)	1 = True	2 = False	3 = Don't Know
Item 2: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 3: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 4: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 5: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 6: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 7: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 8: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 9: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 10: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 11: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 12: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 13: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 14: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 15: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 16: 0 = missing	1 = True	2 = False	3 = Don't Know

**Personal Experience:**

Item 17: 0 = missing (left blank)      1 = True                      2 = False              3 = Don't Know  
(For each response)

Item 18: 0 = missing                      1 = No one      2 = Friend      3 = Relative      4 = Other  
Item (b): 0 = missing                      1 = Younger      2 = About your age      3 = Older  
Item (c): 0 = missing                      1 = Similar      2 = Different                      3 = Don't Know

Item 19: 0 = missing                      1 = No one      2 = Friend      3 = Relative      4 = Other  
Item (b): 0 = missing                      1 = Younger      2 = About your age      3 = Older  
Item (c): 0 = missing                      1 = Similar      2 = Different                      3 = Don't Know

Item 20: 0 = missing                      1 = No one      2 = Friend      3 = Relative      4 = Other  
Item (b): 0 = missing                      1 = Younger      2 = About your age      3 = Older  
Item (c): 0 = missing                      1 = Similar      2 = Different                      3 = Don't Know

Item 21: 0 = missing                      1 = No one      2 = Friend              3 = Relative      4 = Other  
Item (b): 0 = missing                      1 = Younger      2 = About your age      3 = Older  
Item (c): 0 = missing                      1 = Similar      2 = Different                      3 = Don't Know

**Your Opinions about Transplantation and Donation:**

Item 22: 0 = missing                      1 = 1              2 = 2              3 = 3              4 = 4              5 = 5  
(Numbers correspond to coding)

**About yourself/Who are you?**

Item 23: 0 = missing                      1 = 13      2 = 14      3 = 15      4 = 16      5 = 17      6 = 18      7 = 19 (age)

0 = missing                      1 = Male              2 = Female (gender)

0 = missing                      1 = Freshman      2 = Sophomore      3 = Junior      4 = Senior (grade)

0 = missing                      Grade point average (GPA)

0 = missing                      1 = N/A      2 = Nondenominational      3 = Mormon      4 = Other  
5 = Jewish      6 = Catholic (religion)

0 = missing                      1 = English      2 = Bilingual      3 = Spanish      4 = Other (language spoken at home)

**About yourself/Who are you?**

Item 24: 0 = missing	1 = White 4 = Other	2 = Am. In /Al. Native 5 = Asian	3 = Hawaiian Pacific 7 = Hispanic
Item 25: 0 = missing	1 = Grade school 4 = Tech school/cert 7 = Graduate degree	2 = Middle/Jr. High 5 = Some college 8 = Don't Know	3 = HS 6 = Degree
Item 26: 0 = missing	1 = Yes	2 = No	3 = Unsure
Item 27: 0 = missing	1 = Yes	2 = No	3 = DR
Item 28: 0 = missing	1 = Yes	2 = No	3 = DR
Item 29: 0 = missing	1 = Yes	2 = No	3 = Unsure



## APPENDIX R

### POST-SURVEY CODING

#### **Organ Transplantation and Donation:**

Item 1: 0 = missing (left blank)	1 = True	2 = False	3 = Don't Know
Item 2: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 3: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 4: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 5: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 6: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 7: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 8: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 9: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 10: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 11: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 12: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 13: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 14: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 15: 0 = missing	1 = True	2 = False	3 = Don't Know
Item 16: 0 = missing	1 = True	2 = False	3 = Don't Know

**Personal Experience:**

Item 17: 0 = missing (left blank)    1 = True                    2 = False            3 = Don't Know  
(For each response)

Item 18: 0 = missing                    1 = No one    2 = Friend    3 = Relative    4 = Other  
Item (b): 0 = missing                1 = Younger   2 = About your age   3 = Older  
Item (c): 0 = missing                1 = Similar    2 = Different            3 = Don't Know

Item 19: 0 = missing                    1 = No one    2 = Friend    3 = Relative    4 = Other  
Item (b): 0 = missing                1 = Younger   2 = About your age   3 = Older  
Item (c): 0 = missing                1 = Similar    2 = Different            3 = Don't Know

Item 20: 0 = missing                    1 = No one    2 = Friend    3 = Relative    4 = Other  
Item (b): 0 = missing                1 = Younger   2 = About your age   3 = Older  
Item (c): 0 = missing                1 = Similar    2 = Different            3 = Don't Know

Item 21: 0 = missing                    1 = No one    2 = Friend    3 = Relative    4 = Other  
Item (b): 0 = missing                1 = Younger   2 = About your age   3 = Older  
Item (c): 0 = missing                1 = Similar    2 = Different            3 = Don't Know

**Your Opinions about Transplantation and Donation:**

Item 22: 0 = missing                      1 = 1        2 = 2        3 = 3        4 = 4        5 = 5  
(Numbers correspond to coding)

Item 23: 0 = missing                      1 = Yes                                      2 = No                                      3 =  
Unsure

Item (b): 0 = missing                      1 = Yes                                      2 = No                                      3 = DR

Item (c): 0 = missing                      1 = Yes                                      2 = No                                      3 = DR

Item 24: 0 = missing                      1 = Yes                                      2 = No                                      3 =  
Unsure