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# Framing Death: Politics, Meaning, and the Strategic Communication of Organ Donation Messages in South Carolina

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Framing Death: Politics, Meaning, and the Strategic Communication of Organ Donation  
Messages in South Carolina

by

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Submitted in Partial Fulfillment of the Requirements

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## DEDICATION

For B.K.V., who taught me compassion, and for B.R.V. to whom I hope to pass it on.

## ACKNOWLEDGEMENTS

I would like to first acknowledge the work of my committee, Drs. Leatherman, Simmons, Moskowitz, and Corwin, for their advice and encouragement in getting me through the process; Drs. Friedman and Tanner for their mentorship and opening my eyes to the world of health communication and mixed methods analysis; Cleo Mulligan for going above and beyond her duties as graduate assistant and helping me recruit in Sumter County; Lavell Thornton, for being an outstanding colleague and helping me recruit in Richland. Dr. Romel Lacson for creating both a model of research that I can only poorly emulate and helping me make the single most important introduction of my life; Brian and the South Carolina OPO community for supporting my research; Dr. Tamera Beam for letting me tag along to anatomy class; and my wonderful wife Stephanie and darling baby boy Brendan for letting me disappear for weeks to wrap up this final chapter in his education.

## ABSTRACT

This study applies framing theory within a critical-interpretive anthropological context to understand how organ procurement organizations (OPOs) design messages to promote organ donation registration and how cultural factors including notions of embodiment and structural inequalities influence audiences' processing of those messages. The first part of the study employs content analysis to deductively identify OPO-produced message frames. The second part of the study uses focus groups across South Carolina to explore audience reactions to different message frames. Themes from donors and non-donors alike reflected a mistrust of the medical establishment, a keen awareness of structural inequality, and complex notions of embodiment that may be responsible for low donor designation rates. I propose a new model of organ donation registration behavior that incorporates these cultural factors and recommend that effective messaging should first address cultural mistrust of the U.S. healthcare system.

## PREFACE

“Please don’t bury me  
Down in that cold, cold ground  
No, I’d rather have ‘em cut me up  
And pass me all around  
Throw my brain in a hurricane  
And the blind can have my eyes  
And the deaf can take both of my ears  
If they don’t mind the size  
Give my stomach to Milwaukee  
If they run out of beer  
Put my socks in a cedar box  
Just to get ‘em out of here  
Venus De Milo can have my arms  
Look out! I’ve got your nose  
Sell my heart to the junk man  
And give my love to Rose”  
-John Prine, “Please Don’t Bury Me”

Gerald is dead.

I can easily tell that Gerald is dead because Gerald, unlike the other dead people I have seen, cannot be mistaken for anything *except* dead. He is not coated in makeup and placed delicately in an unnecessarily cushioned box as if he were merely sleeping. He is not meticulously posed as a runner captured in mid-sprint, as are the plastinated human models of Gunther von Hagens' *Body Worlds*. He lay instead unadorned on a metal table as two first-year medical students—for lack of a more apt medical description—*peel* him with scalpel and scissors. Forceps and formaldehyde are his grave goods for now, and plastic freezer bags his canopic jars.

Other than his name, I know three things about Gerald: that he is (was?) 49 years old, that he was a “manager,” and that cancer claimed his life. Gerald may well have a fascinating life story; perhaps he climbed Everest in his youth, or coached his daughter's soccer team, or was an amateur magician. But I do not need fantastical conjecture to realize, within minutes of making his acquaintance, that Gerald has changed my life.

.....

I have never been drawn, as a rule, to the morbid. As a teen, I did not hang out in cemeteries. To this day, I devise clever excuses to avoid seeing horror movies with friends. After personal experiences with death, I came to appreciate life rather. It was instead mere curiosity—and perhaps a little boredom—that compels me to accept a friend's invitation to spend a sunny Saturday morning in August with her in a medical school anatomy lab. Her professor would be present to assist students in reviewing for an upcoming exam, and after ensuring that I would follow basic rules of conduct (no photography, no food and drink, no interfering with future physicians, and no



disrespecting the dead), he points me to a box of nitrile gloves, tunes an old boombox to the 80's pop station, and leaves me with my friend, her lab partner, and Gerald.

My friend pats Gerald affectionately on the forehead. “Good morning, Gerald. How are you today?” she asks politely, although clearly not expecting a response. In that instant, she reminds me of Gerald's humanity, which I was all too quick to dismiss under a pretense of clinical detachment. Gerald is a person—a hero, if you will—who in a time of personal crisis made a difficult (it would be for me, anyway) decision to donate his body such that others could learn from it and someday use that knowledge to save lives. I cannot help but romanticize the choice he makes and imagine agonizing conversations with his wife and kids or with the anatomy professor who, I now realize, has met, talked with, and perhaps cried with every person lying on a table in this room when they still they drew breath. Gerald makes me think, for the first time, about the afterlife—not of harps or Hades or questions of the soul, but of what will happen in the corporeal realm when my heart stops beating and my brain stops thinking. What will become of the pieces of me that are left, and will I have the presence of mind and strength of character to make a choice like Gerald's? And is there some inherent contradiction to thinking of these pounds of flesh in front of me as “Gerald” when Gerald himself had clearly decided for himself that his humanity—his Geraldness, if you will—would be separated from his body at death?

This brings me to organ donation. I have been an organ donor since I was 15 years old. The argument for so becoming, courtesy of my parents, is, for me, still the most convincing: there is no good reason *not* to register as a donor. The thought that went into my decision was so scant that, upon reflection, I realize I spent more time deciding

whether or not to smile for my driver's permit photo than I did contemplating my own mortality. In the intervening years, however, I have become utterly fascinated by the topic and the ethical, economic, and anthropological questions it raises. I am drawn to it because the simplicity of the registration process masks so well the complexity of the decision it signifies. I am a donation advocate not because I believe everyone should donate, but because I believe not everyone should. When asked whether I believe individuals should be allowed to sell kidneys, I can rattle off a half-dozen well-reasoned arguments from prominent thinkers on both sides of the issue and tell you where you could get the best price for your own, yet cannot for the life of me articulate my own opinion on the matter. Given the life-altering effects of an organ transplant—from quality of life to financial burden to moral confusion—I do not even know if I would opt for a transplant should I ever need one, yet I would gladly donate my organs to a stranger in a heartbeat (were my doctor quite certain that heartbeat is my last).

At an awareness event held by Donate Life South Carolina, the emcee asked the audience: who among us were organ recipients or family of organ recipients? A number of people raised their hands. Who among us were live donors or family of deceased donors? The rest of the crowd raised their hands. Mine remained at my side. I have no strong personal connection to donation. I have no family or friends who are organ recipients and have never sat in an intensive care unit with a loved one lying before me, facing the heartbreaking decision to donate her organs.

When I talk with others—especially organ donation professionals or advocates—about why I choose to study donation, I don't tell them about meeting Gerald. I don't (always) gush about how gosh-darn *cool* donation and transplantation are, from

technological, economic, and anthropological perspectives. To my shame, I don't risk alienating them by confiding my own ethical struggles with organ donation and its promotion. Instead, I parrot back to them the message I hear and read so clearly and so often: registering as an organ donor is easy and it saves lives, and I want my research to help further that cause. I leave it at that.

The truth, however, is much more complicated.

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## LIST OF ABBREVIATIONS

CIMA .....	Critical-interpretive medical anthropology
DLSC .....	Donate Life South Carolina
DMV .....	Department of Motor Vehicles
KMO .....	Kaiser-Mayer-Olkin measure of sampling adequacy
OPO.....	Organ procurement organization
PCA.....	Principal components analysis
PSA .....	Public service announcement
uDCD .....	Uncontrolled donation after cardiac death



## CHAPTER 1

### INTRODUCTION

Gervais St. is an artery of downtown Columbia, South Carolina, connecting the city's high-rises and university to its nightlife districts. The street runs parallel to the state's capitol building, and thousands of commuters—students, executives, politicians, and government employees—pass through on any given day. On a cold morning in January 2009, passersby may have witnessed a man, dressed in painters' coveralls, scrawling names on a billboard. Had they seen him, perhaps pausing in rush hour traffic, they may have noticed the cadence with which the painter added names to the billboard. A name was added every 11 minutes.

The “living billboard” as it was referred to by the organizations staging the event was, as it turns out, the kickoff of a short-lived campaign created by Donate Life South Carolina (DLSC), the pseudo-governmental nonprofit organization tasked with creating and maintaining the state's organ donor registry (Mursch 2009). Prior to 2009, residents checking the “Yes” to organ donation box when applying for or renewing their drivers' licenses—though they may not have realized it—were not registering any legally-binding orders to have their organs removed and donated after death. They were instead merely registering *intent* to donate organs. Their name went on no official list or in any database. Checking the box for “Yes” or “No” resulted in nothing more official than an icon—a stylized heart overlaid with a “Y” or “N”—printed on the license. Were the worst to happen to that license's holder, and that heart examined by a doctor, nurse, or paramedic

after the declaration of death, it meant—legally speaking—*zilch*. The wishes of the deceased’s next-of-kin were the wishes that would be ultimately respected, regardless of whether they ran counter to those of the deceased.

The launch of S.C.’s organ registry in 2009 by DLSC, as well as those launched around the same time in other state partners of the national organization promoting organ donation, Donate Life America, changed the status quo dramatically. Moving forward, checking the box for “Yes” or registering online with the organization now registered *consent* rather than *intent*. Now a person’s legal consent was registered, making that “Y” on the driver’s license carry the weight of any other legal document, such as a living will or advance directives. It also meant that the name of every person checking that box for “Yes” is entered into an electronic database, searchable by transplant teams across the state and nation.

This shift was huge for DLSC and all of South Carolina’s transplant community. At that time, more than 750 South Carolinians awaited a potentially life-saving organ transplant (LifePoint, Inc. 2009). Every 11 minutes, another name was added to the transplant waiting list. Thus, the living billboard was part of a larger marketing campaign titled “Every 11 Minutes.” In addition to the billboard, somber radio and television ads accompanied a “guerilla” marketing campaign across the state’s metropolitan areas, including slyly adjusted restroom signs (Figure 1.1). Promotional materials were handed out on campuses, at high schools, and scattered about branches of the Department of Motor Vehicles (DMV).

Although I didn’t see the living billboard myself, by January 2009 I had begun research into the field of organ donation. Although my original interest in the topic was

initially more global than local, my imagination captured by images of seedy organ brokers and the devastation they wrought across the global South, my curiosity was piqued by the campaign. My only exposure to organ donation marketing previously was a highly sexualized ad published by the apparently far less puritanical Belgian government (Figure 1.2), and then only in the context of gendered imagery in advertising—not in the context of effective marketing of donation.



Figure 1.1 Sample Every 11 Minutes marketing material

I wondered how the campaign would play across my home state. After all, South Carolina is almost 28% African-American or Black, nearly twice the national average (United States Census Bureau 2015), a group known for its reluctance to donate organs (Jacob Arriola, Perryman, and Doldren 2005). Among the 37 states reporting donor designation rates—that is, the percent of the state’s total population registering legal consent in advance—South Carolina’s 21.7% is higher only than two states, Texas and New York, both with millions more residents than the 4.8 million living in the Palmetto State (Donate Life America 2013). Nationally, the organ donor designation rate is double

that of South Carolina, with 42% of Americans registered. Even a state like Alabama, which usually joins South Carolina near the bottom of many health rankings, boasts a 61% designation rate. Could the urgency of the Every 11 Minutes campaign convince more than 3.7 million people to stand in line at the DMV or register online as an organ donor? Could anything?



Figure 1.2 Belgian donor advertisement – “Reborn to be alive” (Adwomen 2011)

Upon delving into this question, I realized that investigating the cultural, political, and economic forces driving the global inequality in organ transplantation did not necessitate travel to India or South Africa. Within the state, donor designation rates map like other measures of health behavior. A relatively wealthy county like Beaufort tops the list at 58% designation rate, and surely not coincidentally is ranked as the healthiest county in the state, while neighboring Jasper County (24<sup>th</sup> in the state) has only a 31%

designation rate. The county with the lowest ranking for health factors, Allendale, has less than a 14% designation rate (University of Wisconsin Population Health Institute 2015). The factors driving poor health behaviors—smoking, physical activity, and so forth—are well-studied and linked, in recent decades, to structural inequalities (Frieden 2010). Beaufort is predominantly white. Allendale is predominantly Black. Just as it is widely accepted that many health outcomes are driven not by biological but *cultural* factors associated with race, it is safe to assume that it is not genetics that contributes to the low donor designation rate in Allendale, any more than it contributes to low rates of physical activity. Donor designation may instead be simply another reflection of the cultural and structural forces shaping health and health behaviors.

Many advertisements—especially TV and radio ads—exist to elicit a behavior from the audience. Whether that behavior is to purchase a shiny new sports car or to quit smoking, the ultimate effectiveness of an advertisement must be measured by the increase in the desired behavior within the target market. While I will give benefit of the doubt and assume that health communicators working for organ procurement organizations (OPOs) do not, as a rule, while away the hours in expansive Madison Avenue offices, their job is no different than other advertisers: to sell the American public on an image of a product. Their job is to make us imagine ourselves as registered organ donors and, in so doing, convince us that the image is who we want to be. Realistically, while one may doubt that organ donation registration can ever generate enough buzz to elicit 4 A.M. lines outside the DMV on Black Friday, the fact remains that organ donation must be marketed.

This is why I was puzzled by the Every 11 Minutes campaign—by the man on the billboard, the restroom signs, and the somber TV ads. That campaign, costing more than a million dollars according to DLSC’s executive director, was created to convince the 78% of South Carolinians who have not registered as organ donors to do so. Yet how could it possibly achieve that goal? Communication researchers posit that negative messages—those emphasizing loss, such as the deaths of 17 people a day nationwide—are typically less effective than positive ones (Levin, Schneider, and Gaeth 1998). Statistical messages, such as “every 11 minutes a name is added to the transplant waiting list,” are found to be less effective than those emphasizing narratives (Feeley, Marshall, and Reinhart 2006).

Based purely upon health communication literature, DLSC spent its money developing a campaign that should not have been effective. An organization whose name itself is framed in terms of the positive gains associated with organ transplantation—*Donate Life*—selected a core message that was about loss and death. After talking with representatives from the organization, I learned that the campaign was developed by a marketing firm in the Upstate region of the state, who had crafted the message after “internal focus groups”—comprising only the advertising associates themselves—found it to be effective. No evaluation had been conducted, nor did DLSC or its partners have any resources available to do one. This was in 2011, more than a year after the campaign concluded.

On the one hand, I certainly do not envy the health communicators and marketing firms responsible for creating effective advertisements for donation, because it seems, on its face, a losing proposition. Organ transplantation and procurement—or, in the more

traditional and illustrative medical terminology, organ *harvesting*—is an inherently morbid act; upon declaration of brain death, the body is kept “alive” artificially to allow the surgical removal of the healthy organs before the tissue begins breaking down—within minutes or hours of the cessation of circulation. Minutes later, those organs are plopped into other people. And that’s just the solid organs. Corneas, bones, cartilage, and other tissue are cut, sawed, and scraped out. Then the body is stitched up, the ventilators and pumps turned off, and the donor shipped off to the funeral home.

Ultimately, OPOs probably do not want you or me to think about that process. But they do want us to consent to it *now*, so if and when the time comes, they do not have to sit in a hospital room with a grieving wife, father, or child and explain that process in detail, hoping to gain consent in the precious few minutes they have while the organs are still viable. Health communicators and marketers working for OPOs are not selling death *per se*, but they are certainly not selling anything pleasant, so they hoist a painter up on Gervais and try to distract us from our own mortality by reminding us of someone else’s. But I question: is that enough to convince the estimated 55% of America that has not yet registered as organ donors?

## 1.1 DETERMINANTS OF ORGAN DONATION BEHAVIOR

The organ shortage is a double-edged sword, caused both by a dearth of transplantable organs (caused, in part, by a dearth of registered organ donors) and by an ever-growing demand for transplantable organs, as people live longer, unhealthier lives with chronic illness. There are therefore two ways of approaching the issue. One is to identify determinants of donation behavior registration and implement an advertising

campaign designed to elicit a behavioral change. The other is to tackle the rise of chronic illness. This is where things get, shall we say, *squishy*.

Addressing the first problem seems to be the simpler solution. Studies abound in the literature that have attempted to identify, quantify, and modify the factors associated with registration behavior. These studies run the gamut from more orthodox health behavioral constructs such as knowledge, attitudes, and beliefs (cf. Saleem et al. 2009) to more atypical cultural factors such as socioeconomic status, religion and spirituality, and fear and mistrust of the medical profession (cf. Boulware et al. 2002). Researchers have used a number of health behavioral theories to explain their use of these constructs. Some of these applications have been more appropriate than others, regardless of their measured success.

A perfect illustration would be the varied application of Albert Bandura's Social Cognitive Theory, or SCT (Bandura 1986). This theory introduces the construct of self-efficacy, or one's perceived self-confidence to accomplish a task. At one end of the spectrum, a study demonstrated that Dutch high school students who practiced filling out an organ donor card showed higher self-efficacy of registering as organ donors at posttest than those who did not; therefore, they argue, as self-efficacy is a determinant of future behavior, practicing signing a card will lead to greater numbers of registered donors (Reubsaet et al. 2003). This rather shortsighted use of self-efficacy is not a theme in the literature, although proxy measures for actual donation behavior—such as intent, willingness, or attitudes—are quite frequent. Applications of SCT that seem more useful are interventions measuring an individual's self-efficacy as a predictor of communicating donation decisions with one's family after registration (Morgan and Miller 2002; Jacob



Arriola, Perryman, and Doldren 2005; Hall et al. 2007) and, most commonly, interventions designed to increase the self-efficacy of healthcare professionals to approach bereaved families for consent to donate a loved one's organs (Maloney and Altmaier 2003; Blok et al. 2004; Kim, Fisher, and Elliott 2006; Feeley, Tamburlin, and Vincent 2008).

Among public health researchers, the most common theory—whether referenced by name or indirectly through its constructs—is the Theory of Reasoned Action (Fishbein and Ajzen 1975) or its later corollary, Theory of Planned Behavior (Ajzen 1985). These studies tended to rely upon measurement of social norms, attitudes, and beliefs as significant predictors of donation behavior (Radecki and Jaccard 1997; Reubsaet et al. 2001; Feeley 2007; Hyde and White 2007; Bresnahan et al. 2008). Some studies used the Stages of Change or Transtheoretical Model (Prochaska and Velicer 1997) to plan campaigns targeting groups of individuals at various stages or readiness to commit to donation (Feeley and Servoss 2005; Hall et al. 2007). Many studies used theoretical constructs—usually attitudes—without any explicit theory (Cleveland 1975; DeJong et al. 1998; Bidigare and Ellis 2000).

The squishiness of the second question reflects the difficulty that public health and medicine have experienced over the past few years when attempting to tackle chronic illnesses, especially those more prevalent among underrepresented groups such as African-Americans. Public health theories have, until recent years, relied upon individualistic determinants of behavior, such as constructs and theories cited above, while biomedicine has tended to conflate race as a cultural construct with genetic factors associated with skin color, ignoring the cultural and structural underpinnings of disease

(Krieger 2005). African-Americans have higher rates of diabetes, ergo being African-American *causes* diabetes, as the logic would follow.

It is unarguably outside the scope of OPOs to somehow cure poverty, or even to market healthy behaviors to reduce the need for organs. When attempting to solve the first problem, however—the shortage of registered donors—these groups may be relying upon scholarship grounded in the same shortsighted approach to health. Conflating race and ethnicity, the Web site for the U.S. Health Resources and Services Administration suggests that minorities have a greater need for donated organs because of chronic conditions like diabetes that affect those groups disproportionately (Health Resources and Services Administration 2008). No mention is made of structural inequalities that precipitate these illnesses. Scheper-Hughes (2000) argues that the emphasis on racial and ethnic disparities in organ donation and transplantation has obscured these structural problems and created an artificial organ scarcity to redirect blame toward non-donor minorities and away from political and economic systems responsible for health disparities.

Nevertheless, many authors have investigated a perceived unwillingness on the part of ethnic minorities—particularly African-Americans—to consent to organ donation. Yuen and Burton (1998) found that although African-Americans were less knowledgeable about organ donation generally, they were no less willing to donate organs than Whites. The authors suggest that the discrepancy comes from a lack of access to registration materials attributable to socioeconomic factors. Other studies by Siminoff, et al. (2003; 2006) found less willingness to register as donors or consent to donation after the declaration of brain death among African-Americans. They suggest that this

reluctance is not due to a lack of altruism, but because of mistrust of the medical establishment and recognition of structural inequalities underpinning health disparities. Siminoff and Saunderson note that organ procurement in the United States, "...is based upon values that reflect the attitudes and beliefs of the dominant white majority...These data suggest that the valuation of altruism at the expense of other values (such as justice) is questionable" (2000:68) These studies point to an important, critical perspective on organ donation: even when reduced to quantifiable (if not wholly useful) constructs like attitudes, beliefs, or knowledge, the study and promotion of health behavior cannot be divorced from structural inequalities and political economy.

Enter the anthropologist.

## 1.2 THE POLITICAL ECONOMY OF ORGAN DONATION

Donation cannot be understood without turning a critical eye to its complicated history. Margaret Lock (2002) traces the history of organ transplantation to 1913, when Nobel laureate Alexis Carrell discovered that tissues kept in suspended animation outside the body could reproduce and maintain cell function. The first human kidney transplants were performed in the 1950s, but except for cases of identical twins, recipients typically died within days or weeks of surgery. Despite these drawbacks, South African Dr. Christiaan Barnard performed the first human-to-human heart transplant in December 1967—an operation that was met with equal parts fanfare and controversy. Long term survival rates remained grim until the approval of the first anti-rejection drug, cyclosporine, in 1983. Joralemon (1995) credits this new class of drugs as precipitating an exponential increase in the number of organ transplantations performed worldwide. To

support the ever-increasing demand for organs, the very concept of death had to be resituated medically and culturally.

Recognizing the growing need for transplantable organs even before the discovery of cyclosporine, in 1968 the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death met to determine the criteria under which death could be declared despite continued physiological function (Beecher 1969). The phenomenon of brain death is a topic of great interest to anthropologists and transplantation professionals alike. In *Twice Dead*, Margaret Lock (2002) studied the history and meaning of the practice in the United States and Japan, concluding that while brain death has been legalized in both countries, it has hardly been universally accepted among either the public or physicians—particularly in Japan. Worldwide, transplant coordinators and healthcare professionals have demonstrated unease with the practice of declaring death upon cessation of brain function, due in part to confusion over clinical standards (Arie 2008; Kim, Fisher, and Elliott 2006; Lock 2002; Wang and Lin 2009). Bagheri (2005) compared brain death laws across several Asian countries and found highly variable definitions and practices of brain death diagnosis and consent laws. Some authors argue that brain death is a prickly proposition for physicians, as the “dead donor rule”—that the donor must be declared dead before procurement can begin—has focused the debate over organ donation on a redefinition of death rather than demonstrating how the practice is compatible with the “do no harm” philosophy of medicine (Truog and Robinson 2003).

Verheijde, Rady, and McGregor (2007; 2009) further the argument against the dead donor rule, framing their argument within the more recent practice of uncontrolled

donation after cardiac death (uDCD)—when procurement takes place not after cessation of brain function, but within minutes of the unintended cessation of circulation. A patient’s heart can resume beating on its own as late as ten minutes after cardiac arrest, but uDCD protocols state that organ procurement should begin no later than two to three minutes after cardiac arrest. Therefore, it is the donation itself that becomes the cause of death, and the issue is further complicated by the introduction of organ-preservation techniques, which technically interfere with patients’ “Do Not Resuscitate” orders by keeping the body alive using artificial means such as ventilators. The authors find uDCD to be highly problematic with both the public and transplantation professionals, echoed in the findings of others (Borry et al. 2008; Mandell et al. 2006).

Although medical professionals might publicly limit their objections to brain death to questions of diagnostic practice, the work of Lock and others reveals that these objections—though far from trivial in a biomedical society—are rooted as deeply in notions of embodiment as those of non-donors accused of subscribing religious “myths” and superstition. Leslie Sharp notes, “...Organ transfer emerges as an intriguing realm of medical practice because it insists on these forms of mind-body bracketing, yet specialists in the field still struggle to maintain a stable boundary between the two” (2006:44). Brain death is an awkward adaptation of Cartesian duality, in which all personhood is bound up in the electrical impulses of a single organ the size of two fists. As Sharp notes, this notion is scientific reductionism at its most potent, and such a definition presupposes a problematic secularity that puts biomedicine at odds with widely-held cultural beliefs in a metaphysical soul.

Crowley (1998) writes of the frustrating contradiction upon which transplantation laws and medical protocols rest: If mind and body are completely separate, and identity and personhood absent from the tissues of the heart, lungs, or kidney, then what makes the brain so special? That is, given a fully reductionist, dualist model, the brain *should* be viewed as just another organ. No separate category of death should exist. The core of this contradiction lay in biomedicine's insistence that death be a measurable, binary state of existence or nonexistence, despite its ever-more-complicated definition (Sharp 2006). Sharon Kaufman (Kaufman 2005; Kaufman and Morgan 2005) describes how ever-advancing technology and political and economic pressures have changed the process of dying, such that it is no longer merely a simple, widely-understood phenomenon, but instead a complex process in which hospitals and physicians can keep patients alive indefinitely, existing in a liminal state between life and death.

So let us suppose, for a moment, that the body *is* simply a machine, such as a car. Every part of a car is replaceable, and while some may wait to scavenge from an abandoned junker or scrapyard, those with the financial means to do so will simply purchase the replacement part necessary and pay for a mechanic to install it. Given our analogy, one in need of a kidney could hope to beat the odds and wait for a genetically compatible donor to break down beyond repair. Or, alternatively, he could find someone selling the appropriate part, buy it, and ask a surgeon to transplant it. Yet despite a biomedical model that attempts to separate the physical body from the social body and organs from embodied meaning, organs are not treated like car parts. As Schweda and Schicktanz (2009) discovered in a rare qualitative study of organ donation attitudes, although participants frequently referred to the body using the mechanistic analogy of the

car, their attitudes reflected much more complicated notions of mind, body, and identity. They conclude that even if people do talk about the body in terms of total ownership and replaceable parts, most do not necessarily consider it to be “some piece of private property available for commerce.”

Herein lies another contradiction in the organ debate. Biomedicine promotes a Cartesian view of mind and body, thereby justifying the declaration of brain death, but a majority of medical professionals, legislators, and citizens do not see organs as wholly mechanical parts. Although they can be swapped out like a broken carburetor, the *sale and purchase* of human organs are expressly prohibited by national and international law.

As problematic as brain death may be, it has not generated the same amount of controversy within public, medical, and academic spheres as the sale of human organs. Compensation for organ donation has been outlawed in the United States since the passage of the Uniform Anatomical Gift Act in 1968 (Sadler, Sadler, and Stason 1968). Nevertheless, despite the illegality of organ sales throughout the world, a market persists. Scholars and physicians alike have denounced the sale of black market organs, usually obtained from the abysmally impoverished in countries like India, Pakistan, the Philippines or from executed prisoners in China, and sold to wealthy Americans, Western Europeans, Australians, Japanese, and Israelis (Rothman et al. 1997; Scheper-Hughes 2000; Shimazono 2007; Griffin and Fitzpatrick 2009). While highly critical of unscrupulous organ brokers and physicians and the lack of government regulation or oversight, these articles refrain from castigating the recipients. Daniel Asa Rose (2010) presents a memoir of his journey to China in search of a kidney for his ailing cousin in his book *Larry's Kidney*. Although both author and recipient acknowledge the

moral quandary of paying their way to bypass the Chinese waiting list and receive a kidney from an executed prisoner, Rose rationalizes the decision by saying that given the opportunity, almost anyone would do everything in his power to save a loved one. Nevertheless, the availability of ill-begotten organs to rich foreigners has sparked a great many moral panics in marginalized populations (Campion-Vincent 1997).

Set against this backdrop rages a debate over the ethics of a regulated kidney market. Arthur Matas (2004) and Erin and Harris (2003) argue for such a system—in which a live donor is paid a substantial sum from the government-sponsored transplant foundation, and the kidney given to the top candidate on the fair waiting list—to promote individual autonomy, reduce kidney scarcity, and lower overall healthcare costs. Friedman and Friedman (2006) agree with his proposal, likening the ban on kidney sales to Prohibition under the 18<sup>th</sup> Amendment, and saying that it is not the government's responsibility to protect the individual from victimless risky behaviors. Others disagree, saying that the social consequences of undermining the altruistic system of organ gifting are too great; the poor will be exploited, and the free market reasoning behind such a system could lead to an elimination of an equitable waiting list (Kahn and Delmonico 2004). Mosimann (2002) adds that commodification of organs may lead also to an increased organ shortage, as potential donors may be less inclined to donate if they view their organs as a commodity. A system of compensated kidney donation is currently practiced in Iran, where both donor and recipient apply to a sponsored charity that matches the two and pays a fixed sum to the donor, and while kidney transplants are up, the system does have its flaws; it may encourage private sales of kidneys, even if it precludes brokerage (Bagheri 2006). Conversely, Amir Daar (1996) suggests that



donation in Saudi Arabia can be increased through the creation of a charter that encourages altruistic living donation and suggests that whenever possible, transplant physicians and centers should forego professional fees such that the message of altruism rings true.

Just as with brain death, critical-interpretive medical anthropology, or CIMA, holds the key to situating the commodification controversy along the intersections of the “three bodies.” A kidney can be understood as a piece of the physical body, as a symbol imbued with sometimes contradictory meaning—as will be discussed later—or as an item with a very real, calculable market value and existing within the body politic, subject to biopolitical power. Scheper-Hughes (2000) notes that in both the black market and the legal waiting list, organs tend to follow traditional models of commodity flow: from global South to global North, from black to white, from female to male, and from poor to rich.

While the illegality of the organ market dissuades the exploitation of marginalized populations, it hardly reverses the commodification of the body. Hospitals, physicians, organ procurement specialists, and countless other agents benefit financially from transplant procedures that can cost patients and their insurance companies hundreds of thousands of dollars (National Foundation for Transplants 2009). News reports abound of celebrities like Apple founder Steve Jobs who spend millions of dollars to game the transplant waiting list to greatly increase their chances of a match (Saletan 2011), while those less fortunate are finding themselves unable to pay as insurance companies and government cut back on medical benefits (Satel 2010). While the anthropologists, ethicists, and transplant professionals debate the morality of a legalized organ market, the

fact remains that one already exists—disguised as an equitable system of distribution that benefits all and favors no one.

### 1.3 COMPETING MEANINGS OF ORGANS

Brain death is a prime example of the competing meanings of embodiment endemic to organ transplantation as a phenomenon. Sharp's seminal *Strange Harvest* (2006) effectively covers these contradictory meanings of organs as promoted throughout the organ transfer process. A large portion of her work is dedicated to demonstrating the strategies of organ procurement organizations (OPOs) to keep donor kin and recipients from communicating with one another, precisely so their contradictory messages do not get mixed. Donor kin are told that their loved one will live on in another person, saving their life. Recipients, on the other hand, are reminded that their new organ is entirely their own to prevent psychological rejection. Donald Joralemon (1995) details the psychological rejection process, drawing on Mauss to explain how organ recipients, given the "gift of life," experience the "tyranny of the gift." Reminded daily by nauseating and debilitating anti-rejection drugs that their transplanted organ is foreign tissue, recipients frequently lapse into life-altering depression over a debt that can never be repaid. The debt is two-fold: not only can they never repay the symbolic gift of the organ, but the financial costs—which can run more than a million dollars without health insurance—will burden most recipients for the rest of their lives (Transplant Living | Financing A Transplant | Costs n.d.). Sharp points out that while public donor memorials can be important catharsis for recipients, donor kin are typically kept away from the events to prevent reinforcing the idea of the Other living within.

Donation communication campaigns also introduce competing messages. Siminoff and Chillag (1999) scrutinized the narrative themes of donation advertising through ethnographic research, concluding that a reliance upon the “gift of life” narrative may actually lead to increased reluctance to donate because these themes are inappropriate to the potential donor, who does not typically view the complex donation process as an exchange, while recipients face more psychological rejection as a result of the “tyranny of the gift.” Sque, et al. followed this line of research and found that although the “gift of life” discourse can actually motivate families to donate a loved one’s organs, when donation is called a “sacrifice” by OPOs, it can evoke gruesome images of harm done to the donor’s body, such as those of ritualistic human sacrifice or the suffering of Christ upon the crucifix (Sque, Payne, and Macleod Clark 2006).

#### 1.4 RECONCILING DISCIPLINES

Organ donation registration perfectly illustrates the problems of a zero-sum approach to health behavior research, by suggesting the interests of the medical establishment are inherently and diametrically opposed to the interests of the communities it purports to serve. Some critical anthropology can yield a trap in which it becomes easy to humanize the victim with stories of individual unmet need for organs and generalize the oppressor, as when the medical transplant community and OPOs are lumped together with black market organ brokers, as in Scheper-Hughes (2000; 2004). While anthropology (and health promotion and education alike) has in recent decades given a powerful voice to the disenfranchised and shone a light on those powerful entities that harm, through mere neglect or institutionalized violence, the marginalized and vulnerable, perhaps the decision to position ourselves at the bottom looking up yields its

own peculiar myopia. This is not a new phenomenon within the field. Laura Nader (1972) writes of the preference of anthropologists to study, as she puts it, “the underdog,” chastises the field for neglecting to “study up,” or conduct fieldwork and detailed analysis of the power structures responsible for inequality or oppression. In an effort to ferret out the institutions and broad epistemologies (such as the biomedical paradigm) responsible for causing or perpetuating structural inequality, critical medical anthropology has done very little to identify or analyze individuals and groups within the structure that fight for the very same causes championed by anthropologists and grassroots movements. In the case of organ donation, medical professionals, OPOs, and government certainly share some responsibility for the inequities of organ transplantation across the nation and world. Nevertheless, the professionals within these organizations are working to increase the supply of organs for underrepresented populations, not restrict it.

As demonstrated throughout the literature, CIMA represents two themes: the critique of biomedical knowledge production and the effects of political and economic structure on the “three bodies” described by Scheper-Hughes and Lock. These threads are intertwined, and though one may be stressed over the other, both can be seen in every critical-interpretive study. Nevertheless, as seen most clearly in studies of structural violence, “structure” becomes a problematic concept if not properly defined. A critical medical anthropology that recognizes the impact of political-economy is a vital step toward social justice in health, but rarely is a view from below matched with a “view from above.” That is, “structure” becomes a catch-all phrase for all entities more politically or economically powerful than the informant, from the specific—individual

physicians, government officials, military officers, NGOs—to the vague—the global North, the ethnic majority, and so on.

Surely this dehumanization of political and economic powers is not merely due to preconceived biases or lack of consideration to the faces behind these forces. More likely, it is a question of access. The “critical” aspect of critical anthropology is not one which engenders favorable consideration for the researcher seeking audience with dictators, war criminals, or elite government officials. In some circumstances, the anthropologist may be seen as an investigative journalist without the weight of a cable news network or high circulation paper as channels demanding cooperation—simply put, an annoyance and a liability. As Nader notes, “Telling it like it is may be perceived as muckraking by the subjects of study” (1972:21).

Yet the result of not studying up is that it creates scenarios that presuppose the most sinister of forces locking horns with the marginalized and, by extension, the anthropologist. Using a study of illicit organ transplantation to argue for a “militant anthropology,” Scheper-Hughes writes that she positions herself “...on the ‘other side’ of the transplant equation in order to represent the silent or silenced organ donors, I am attempting to reconstitute living donors as rights-bearing individuals and persons rather than as faceless organs ‘suppliers’, ‘vendors’ or living cadavers and medical material for transplant procedures” (2004:64). On the other side, “the corrective field of bioethics and the profession of transplant medicine have both capitulated to the dominant market ethos... Transplant surgeons sometimes see themselves as ‘above the law’” (2004:61).

The public health institution in America, despite its governmental ties, does not fit so easily into this mold. Public health represents an amorphous collaboration among

government, healthcare providers, nonprofits, churches, communities, and individuals trying—in the face of scarce financial and human resources—to win the battles against illness and death that humanity has lost since time immemorial. Although American public health’s pedigree owes as much to the tragedies of eugenic movements as it does to social medicine, the shift to health disparities in recent decades—and my own personal experience working for governmental public health—suggest that its goals are not incongruent with the “militant” anthropology Scheper-Hughes proposes. Without a careful examination of definitions and boundaries of “structure,” I worry that, as a critical anthropologist, I run the risk of tilting at windmills, creating antagonistic relationships between themselves and structural institutions when no such relationships may actually exist.

I offer this characterization not to suggest that American public health is free of prejudice or responsibility for the state of health—particularly among underserved populations—in the United States. I instead use it to provide the context for a parallel thread to the grassroots anthropology of our time. For just as critical medical anthropology, empathizing the plight of the marginalized, can allow its critical eye to blind it to the humanity that underpins even the most structural of power relations, so too does public health hesitate to critically examine the ideologies underpinning its practices (cf. Bhatia 2003). As Good (1994), Krieger (2000), Pelto and Pelto (1997) and others suggest, public health and medicine have historically relied too heavily upon the health behavior and risk factor models of disease at the expense of critical examination of structural factors, though that paradigm is shifting (cf. Frieden 2010). No anthropologist will argue that a lack of exercise and unhealthy eating are not responsible for obesity and

heart disease, or that African-Americans have higher rates of stroke than White populations. The question is how much the individual is responsible for or has control over lifestyle “choices,” and how poorly-defined, biological constructions of race mask socioeconomic disparity. While health behavior theories offer conveniently quantifiable models for intervention, they overemphasize individual agency in contexts where, quite frequently, they are structurally constrained. In so doing, these models enable structural inequalities to persist.

My objection to the corpus of organ donation research is this: on one side of the divide, you have an overly-reductionist biomedical approach that paints donors and non-donors with broad strokes of selfless versus selfish, educated versus ignorant, rational versus superstitious. On the other, anthropologists have revealed (or created) an impossibly tangled mess of ethics, history, and meaning, that leaves no room for intervention; if the transplantation system or technology itself is corrupt, any attempt to increase donation registration is itself feeding a system of inequality. Yet both models presuppose that the average American’s donation registration decision is—at its core—a product of forces that are ultimately outside his or her sphere of control, the decision made either by clever campaigns or by entrenched cultural memory. But what if links could be found between culture and behavioral outcomes—in which complicated relationships and schemata are not reduced to a single box labeled “culture” on a logic model, but which could be used to inform (rather than problematize) effective organ donation communication campaigns? Understanding how meaning is created and interpreted within a political-economic context can provide better insight into how

donation registration behavior occurs. The first step is understanding the concept of intersubjectivity, and how donation communication draws upon it.

### 1.5 INTERSUBJECTIVITY

The question of “what is real?” has been the undercurrent of scientific and philosophical thought since the beginning of history. From Plato’s allegory of the cave to recent debates over the rigor of qualitative data, the objective-subjective dichotomy has proven problematic to scholars of all disciplines. Within anthropology, scholars argue about the primacy of objective models of the world versus “moral” ones (D’Andrade 1995; Scheper-Hughes 1995); within sociolinguistics, whether theories of subjectivity and identity can emerge from objective data (Sacks, Schegloff, and Jefferson 1974; Schegloff 1992; Land and Kitzinger 2005; Park 2007); within communication research, whether message frames are constructed by content creators or exist within a collective or cultural conscious (Goffman 1986; Scheufele 1999; Van Gorp 2007); and within health research, whether qualitative studies can produce the same validity as quantitative ones (Baum 1995; Eakin and Mykhalovskiy 2003). With the appropriate application of methods from each of these fields, however, researchers can get at questions of subjective meanings while still remaining grounded in valid, reliable data. Because although subjectivity—internal symbols and meanings—cannot be measured by objective, positivist standards, the expression of such subjectivity within a culture *can* be seen and *can* be measured. It is this “intersubjectivity” that gives symbols their meaning within culture and gives researchers an opportunity to rigorously study them.

In his ethnological analysis of negotiation of individual and shared social identity among cultures in Australia and Sierra Leone, Jackson (1998:15) succinctly describes



intersubjectivity as “the singular universal.” That is, it was a response to a structuralist, positivist turn in anthropology and sociology that posited that culture could be studied objectively. Thinkers like Durkheim (1915), Malinowski (1922), and Lévi-Strauss (1967) argue that cultural phenomena such as religion could be broken into component parts and studied with the application of the scientific method. Function and practice, as visible and inferable, could be studied objectively, whereas *meaning*—the subjective—was invisible. Goffman (1986), Bourdieu (1977), and Geertz (1973) disagreed; while the subjective may indeed be internal, it is experienced socially. Writes Jackson of the new theoretical turn, intersubjectivity sees the self not as a single existence, but as an “arrested moment artificially isolated from the flux of ‘interindividual’ life” (1998:6).

Intersubjectivity suggests that meaning is ratified as it is experienced socially. Simply put, certain symbols are shared universally within cultures. While intersubjective scholars agree that these subjective meanings cannot be studied objectively, they disagree that they cannot or should not be studied at all. Through studies of practice and participant observation, researchers can tap into the intersubjective and experience phenomena that are social expressions of individual subjectivity. Framing theory and interpretive anthropology, to be discussed later, both acknowledge the centrality of intersubjective meanings.

Just as Hall (1973) suggests that culture is communication, then communication itself must be culture. Language and talk stand as examples of intersubjectivity, as both exist as expressions of subjectivity that operate only as shared social phenomena. Health communication is a specialized form of communication, but operates in the same way. Kreuter, et al. note the advantages of narrative-based health communication may lie in

“its familiarity as a basic mode of human interaction (2007:222). Slater suggests that health communication campaigns target audience segments by identifying “people who are similar in important respects and [tailoring] one’s communication content and delivery to them” (1995:187), pointing to shared knowledge, concerns, and behavior. Health communication researchers recognize, therefore, that a message’s structure and content are constructed around intersubjective forms—individual characteristics shared within a culture.

Framing theory is one of the most popular theories in mass communication scholarly publications (Bryant and Miron 2004; McQuail 2005; Scheufele 1999). As it has become more popular, so too have its applications become more widely varied and inconsistent, as Entman (1993) argues. In an attempt to reconcile the “fractured paradigm,” Entman defines framing as the process by which communicators “select some aspect of a perceived reality and make them more salient in a communicating text, in such a way as to promote a particular problem definition, causal interpretation, moral evaluation, and/or treatment recommendation for the item described” (1993:52). The confusion over the term stems from the ambiguity of Goffman’s commonly cited treatise on frame analysis, in which he defines frames as “principles of organization which govern events—at least social ones—and our involvement in them” (Goffman 1986:7). Kahneman and Tversky (2000) demonstrate a link between the framing of an issue and behavioral decisions made as a result, suggesting that seemingly irrational behavior can be explained discovering the ways messages and issues have been framed for the individual. In his essay “The Constructionist Approach to Framing,” Baldwin Van Gorp (2007) uses culture to tie together the disparate, multidisciplinary theory. Frames, he

writes, are culturally-formed and exist within the collective conscious and trigger psychological schemata that guide an individual to a particular interpretation. Shoemaker and Reese (1996) agree, suggesting that a cultural “macrostructure” impacts individual interpretations of media content. That is, frames themselves are intersubjective.

As humans operating within society and culture, message makers are influenced by this macrostructure (an assumption that will be tested in this research), then they attempt to tap into shared cultural values, memories, beliefs, and histories to elicit behavioral change. While this view relies on an assumption of cultural universals that much recent anthropology tends to eschew, it does provide insight into how mass communication researchers (and advertisers) operate. The biomedical/health communication model appears to operate under three additional assumptions:

1. The discourse created by biomedical practitioners is fundamentally objective and is not itself influenced by their own cultural biases.
2. The strategic communication of messages based on these fundamentally objective truths will result in measurable behavioral change.
3. The goal of health communication should be making these objective truths palatable and understandable to target audiences.

Yet critical scholars have tested these assumptions and found them wanting. In their noteworthy work in Venezuela, Briggs and Mantini-Briggs, combine linguistic analysis and critical-interpretive theory to examine discourse about cholera during and after an outbreak among the *indígenos*. They discovered that not only was the epidemic underreported by authorities, but official discourse about the epidemic racialized the disease and indigenous narratives were shaped by political and economic marginalization

(Briggs 2001; Briggs and Mantini-Briggs 2003; Briggs 2004; Briggs 2005). Treichler's (1987) examination of medical discourse in the early days of the AIDS epidemic is another perfect illustration of assumptions of objective, reductionist science in the biomedical model, as she demonstrates how the cultural meanings of homosexuality tainted the "objective" study of AIDS and policy and contributed to its uncontrolled spread throughout the world.

The application of framing theory within a critical-interpretive context can allow the anthropologist to better understand the influence of culture on the whole of the communication process—from channel to message to receiver—and in so doing grasp at that which is intersubjective within a culture. Framing theory is a perfect methodological complement to a CIMA theoretical model, as it enables the researcher to better unpack the *meaning* of the messages within a political and economic context. By delving into the elements of a message, one can—to some extent—"study up" to understand the meaning intended or expressed by OPOs within a cultural context. Then, by studying the discourse created about these messages among target audiences, one can begin to tease out how political economy and culturally entrenched values influence reactions and, consequently, behavior. The overlapping study of the "view from above" and the "view from below" will not only reveal insight into shared—or perhaps competing—meanings of organ donation, but will also offer evidence for practicing health communicators as to effective message frames to promote organ donation registration.

I will use framing theory to attempt to identify the messages used by OPOs to promote organ donation, without relying upon *a priori* selections that are biased by my interpretation of messages, viewed as they would be through the eyes of researcher,

donor, and communicator. By breaking down messages into their individual elements and seeing how those elements interact to form messages, I can better identify the mechanisms through which OPOs attempt to elicit behavior change. By prompting discourse surrounding those messages and eliciting the individual and cultural interpretations of those messages within a political and economic framework, I can begin to tease out how messages are mediated by the cultural macrostructure. Respecting and understanding the influence culture has on health behavior is the key to successfully marketing donation.

## CHAPTER 2

### RESEARCH DESIGN AND METHODS

As discussed previously, organ donation has been studied extensively from both anthropological and health communication perspectives. Anthropologists have explored the meanings of organs, death, and brain death from critical and interpretive perspectives (Lock 2002; Sharp 2006; Scheper-Hughes 2000; Scheper-Hughes 2004; Hogle 1995; Joralemon 1995) while health communication scholars have sought to discover the formula to effective marketing of donation registration and familial consent to donation. I believe that an integrated, two-part research approach can further understanding of both topics.

The current study seeks to answer three research questions:

1. What message frames and other attributes of advertising are used to promote organ donation advertising?
2. What message frames or elements of communication are effective at promoting organ donation registration?
3. What individual, cultural, and structural factors drive one's decision to donate or not to donate his or her organs?

To answer the first question, I will demonstrate the effectiveness of a rigorous, quantitatively driven content analysis for identifying and classifying message frames. I will then use the results of that study to answer the second and third questions, showing videos with distinct framing to explore discourse surrounding organ donation among

donors and non-donors alike. In so doing, I will identify cultural factors that influence both the processing of pro-donation messages and, ultimately, donation registration behavior. The overall research design is shown in the figure below. I will explain each step in the process and how the overall research design will yield answers to the two research questions.

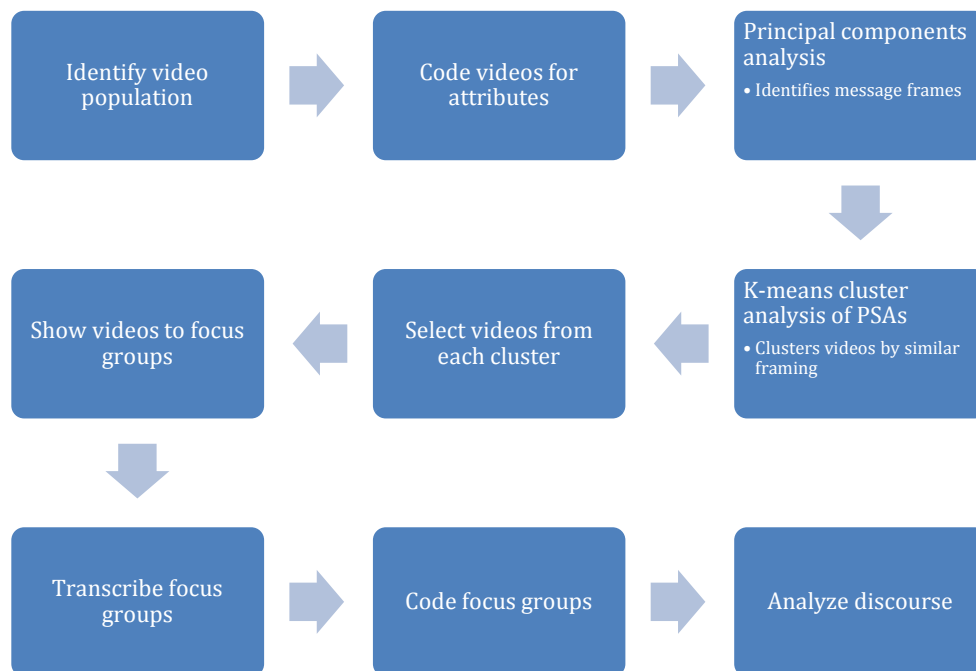


Figure 2.1 Structure of methods

As an anthropologist, I believe firmly in the exploratory power of qualitative methods in teasing out the otherwise invisible or unspoken threads of culture that underpin people's schemas for health decision making. Having worked in public health policy for several years, I also recognize the importance of quantitative methods for identifying patterns within data that challenge preconceptions. To that end, this research employs both qualitative and quantitative approaches to answer these questions.

Many studies of organ donation have used preconceived, and in some cases, dichotomous frames to determine message effectiveness. Although I do not doubt the validity of these studies' results, I have worried that researchers have potentially limited themselves by studying frames—such as “the gift of life” or “sacrifice”—*a priori*. Where do these frames come from? Do they truly represent the whole of message framing around organ donation? Because it is possible that the most effective frame for promoting organ donation may never have been studied due to a tendency within the literature to rely upon the same frames repeatedly without thought to others (cf. Morgan et al. 2007; Tian 2010), I did not wish to limit my exploration of themes and meanings of organ donation among focus groups by exposing them to a non-representative (unscientific) sample of advertisements.

In the first part of the study, I conducted a content analysis to deductively identify the message frames used within the population of videos posted to the YouTube channels of the state chapters or partners of Donate Life America. After coding each video for key elements, I used statistical methods to identify message frames and cluster public service announcements (PSAs) by common theme. I selected PSAs for more in-depth study because, as they are by definition “public” and therefore designed to address external audiences. They are a tool used by OPOs to elicit behavioral change.

My research yielded nine clusters of videos. From six of these clusters (one was excluded because it included feature-length documentaries unsuitable for focus group response and two clusters included only compilations of videos appearing in other clusters), I selected a video to play for the focus groups, and whenever possible, selected videos with apparently equivalent production values so as not to distract participants by



asking them to respond to videos of amateur quality next to ones created by professionals. I also included four additional videos to see how different frame elements could affect focus group responses.

In the second part of the study, I played these videos for focus groups in three counties across South Carolina, ostensibly to learn how different frames and factors shaped different groups' responses to donation promotion messaging. More subtly, I used these videos as a point of entry to explore cultural meanings behind organs and factors driving donation behavior among groups of participants of different ages, genders, ethnicities, and backgrounds. An honest discussion of mortality does not come easily even among friends—much less so among groups of strangers. The use of these videos therefore serves also as a kind of neutral focal point for these discussions—a diving board to deeper waters.

## 2.1 CONTENT ANALYSIS

Although originally popular in mass communication research, content analysis has gained prevalence within health communication. Nandy and Sarvela (1997) provide an overview of its use within public health education and suggest that content analysis is a highly relevant method that allows health communicators to strategically plan messages around media portrayals of health issues. Tanner and Friedman (2011b) explored health information and sourcing on TV news Web sites. Keelan et al. (2007) conducted a content analysis of YouTube videos covering immunization, finding that approximately half of the videos posted contained anti-immunization or factually inaccurate messages. Sokol et al. (2010) analyzed the content of direct-to-consumer pharmaceutical advertising

in magazines, concluding that such ads were prevalent and raised the possibility of confusing readers as to treatment options.

While the use of quantitative methods as a method for drawing inferences about culture may be somewhat unusual within a field typically employing qualitative ones, it is not unheard of. Dressler, et al apply a similar methodology to their studies of cultural consonance (Dressler and Bindon 2000; Dressler et al. 2005; Dressler et al. 2007). On seeking a valid and reliable technique for anthropological measurement, they write, “The value of anthropological research would be enhanced by systematic measurement procedures; however, considerable effort must be taken not to lose the very thing that makes hypothesis testing in anthropological research most useful, which is the sensitivity to local meaning and context in measurement” (Dressler et al. 2005:333).

I attempt to employ a rigorous mixed-methods approach to content analysis to find the intersubjective frames used by OPOs, just as Dressler searches for a “cultural model” shared by his respondents. Such a method can reduce my own conscious or unconscious bias on the selection of frames. As Collier writes, “Content analysis, by itself, does not demonstrate how viewers understand or value what they see or hear. Still, content analysis shows what is given priority or salience and what is not” (2003:26). What I view as salient features of a set of videos may not appear salient to someone viewing these videos through the lenses of their experiences and beliefs. What I view as a central message may be ignored or interpreted entirely differently by another. If I am to attempt to understand the meanings of donation promoted by OPOs through framing, I cannot approach the question by cherry-picking based on my perceptions. I argue that coding for the presence or absence of key attributes and using statistical analysis to see

how those attributes form frames meets Dressler's call for a "valid" and "reliable" measurement for anthropological research.

The sample of videos analyzed for this content analysis includes all YouTube videos posted on the official channels of local and regional OPO partners of Donate Life America. I limited the scope of the study to videos posted by OPOs, professional organizations with a defined agenda—the promotion and coordination of organ donation and transplantation—to allow for a focused content analysis and better understand their strategic communications. In 2007, YouTube introduced special pages called "channels" that allow organizations to house all of their uploaded and shared videos and enable users to subscribe and be notified of new additions. I identified the channels associated with each OPO by visiting each OPO's website or Facebook page and searching for links to these videos, then found additional channels not posted on the websites using YouTube's search function and the channel owners' contact information. These channels yielded 453 videos posted between February 22, 2008 (the date of the first video posted on an OPO's channel) and February 15, 2011. Of these 453, I excluded 76 from analysis after the coding phase because they did not include any message related to organ donation, yielding a final sample of 377<sup>1</sup>. Videos that met the basic criteria were included regardless of whether or not the OPO self-identified in the video itself<sup>2</sup>.

Van Gorp (2007) suggests that selecting simplistic frames for which to code (e.g., "positive" and "negative") glosses over the complexities of frames' structured meanings

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<sup>1</sup> Examples of excluded videos were recordings of musical acts performing during OPO fundraisers that did not include any mention of organ donation.

<sup>2</sup> OPOs self-identified and included a website, phone number, or physical addresses in 52% (n=195) of the videos included in the study.

while Matthes and Kohring (2008) contend that most content analyses of media frames analyze not the frames embedded within a cultural text, but instead those frames selected *a priori* by a biased researcher. Both researchers recommend coding content for frame “elements”—individual binary variables—emerging inductively or selected through literature review, followed by a quantitative cluster analysis to see how codes are grouped over a sample of documents. These clusters, they argue, are the frames themselves, arrived at through reliable scientific investigation. I modeled the coding procedure after their research in an effort to increase understanding of the complexity of frames about organ donation presented by OPOs.

I initially coded basic characteristics such as length, date of posting, and number of views and then coded for video type—public service announcement (PSA), “informal” interview (sit-downs at events or functions, typically shot or edited on-the-fly), “formal” interview (longer, edited interviews typically shot in a studio setting), press conference, event or function (such as donor memorial slideshows), or other. Videos were also coded as to whether or not they were “professional,” or exhibited high enough production values to suggest the involvement of trained filmmakers and appear as broadcast quality. Most topic variables—the “problem definition” of donation frames (Matthes and Kohring 2008)—were chosen based on constructs used in other studies of organ donation attitudes or communication: life and giving (Sharp 2006; Siminoff and Chillag 1999; Sque, Payne, and Macleod Clark 2006), death (McNamara et al. 1999), brain death (Lock 2002), waiting/disease/need, religion (Tian 2010a), sacrifice (Sque, Payne, and Macleod Clark 2006), remembrance (Sharp 2006), misconceptions (Morgan et al. 2007), hero (Sharp 2006), and disparities (Siminoff, Burant, and Ibrahim 2006). Others—

waiting/disease/need, gratitude, and obligation—emerged as the codebook evolved during the inter-rater reliability process. I adapted codes for statistical and narrative structure from Feeley and colleagues (2006). Categories for primary focus or “treatment”—to increase knowledge or raise awareness about organ donation, provide tools or knowledge for registration, chronicle event or function, “humanize” donation, or other—were developed during the inter-rater reliability process. I coded videos for one of these primary foci if at least 75% of its content featured that treatment of donation, following examples set by other content analyses (Tanner and Friedman 2011a; Tanner and Friedman 2011b; Tanner et al. 2009). I developed a Microsoft Access database for coding and exported the results to an Excel spreadsheet readable by SAS 9.2.

To establish the reliability of the codebook, another researcher and I coded a sample of videos, following a training phase in which the codebook was updated to clarify definitions based on discrepancies of interpretations of codes. Inter-rater reliability was calculated for a 10% (n=37) random sample (Tanner and Friedman 2011a; Tanner et al. 2009). The Cohen’s Kappa statistic, which measures inter-rater agreement of categorical variables between two coders (Cohen, 1960), was calculated for speaker characteristics (mean  $k = 1.00$ ), video type ( $k = 0.877$ ), primary focus ( $k = 1.00$ ), statistical structure ( $k = 0.92$ ), narrative structure ( $k = 0.857$ ), and thematic variables (mean  $k = 0.936$ , range =  $0.841 - 1$ ). These scores indicate “almost perfect” coder agreement according to the criteria developed by Landis and Koch (1977).

SAS 9.2 was used for all quantitative analysis. Non parametric frequencies and percentages were calculated for all variables. To explore the frames used for strategic communication by OPOs, I used a principal components analysis (PCA) with a Varimax

(orthogonal) rotation on three video types—public service announcements (PSAs), informal interviews, and formal interviews. PSAs are videos intended to promote organ donation and typically played for a general audience, such as on TV. Informal interviews are unedited, “man-on-the-street” style videos in which a donor, recipient, OPO representative, or similar figure talks about donation, but is typically longer than a PSA and not necessarily shown to promote donation. Formal interviews are similar to informal interviews in that a speaker discusses donation, but are professionally produced, edited, or scripted.

PCA reduces the number of variables by exploring their relationship to one another to find underlying structure; variables that load strongly onto a single factor form a thematic frame. Thematic variables that did not achieve a minimum Kaiser-Meyer Olkin measure of sampling adequacy (KMO) of 0.5 were excluded from the analysis. The recommendations of Stevens (1986) determined the statistical significance of each factor loading. I did not include the structural elements of Statistical and Narrative in the PCA as these two variables were strongly and inversely correlated with each other; separate factor and chi-square tests proved more appropriate at discovering their relationship with the different frame elements.

Because themes can be linked and a single video may address multiple frame elements with varying emphasis, I performed a k-means cluster analysis using the dataset created by the PCA to see how observations formed groups around thematic factors. The k-means analysis used a least squares estimation of Euclidean distances, and the optimal number of clusters was determined by plotting the cubic clustering criterion (CCC) against the number of clusters (SAS Institute Inc. 1983). This operation was performed

for PSAs, informal interviews, and formal interviews<sup>3</sup>. Finally, I validated the clusters with a discriminant analysis using the original 13 thematic variables.

Why bother clustering the videos after identifying the frames—the original intent of this phase of study? Frames are not necessarily discrete categories, into which a video cleanly falls. A video could potentially be framed multiple ways within a single message, or emphasize one frame more than another. PCA provided factor loadings for each video based on frame elements. By clustering around factor loadings, I could find similarly framed videos and select a video from each cluster to show focus groups. I could also use the clusters as a subjective self-check on the appropriateness of the statistical methods; if videos within a cluster all seemed to share a common message, I could feel confident that the content analysis was successful.

I also confirmed the findings of both the PCA and the cluster analysis qualitatively. I felt comfortable that the frames identified in the PCA made sense, especially seeing as how “the gift of life” appeared in some form, as one would expect given the literature’s focus on that particular frame. Having viewed each video at least several times, I also confirmed that the nine clusters for PSAs seemed reasonable. As one would also expect, different videos produced within a single campaign tended to cluster together, as they would be framed with a similar message.

After identifying the clusters, I selected one video to show to focus groups from each of six clusters representing different frames. I excluded two clusters because they included only compilations of videos appearing in other clusters and excluded the third

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<sup>3</sup> The skewed distribution of formal interview factors loadings required a logarithmic transformation before clustering

because it included only three videos, each greater than 60 minutes in length. I chose videos from these six clusters subjectively, controlling for relatively similar production values when possible, and ensuring diversity of gender, age, and race. I also looked to select videos that seemed, by my estimation, representative of a particular frame cluster. I selected four additional videos that had one or more unique elements unique within their clusters to see how those elements impacted focus group reactions. The videos selected are described in Chapter Four.

## 2.2 FOCUS GROUPS

My original research plan called for recruiting focus group participants between the ages of 18 and 32 from three counties in South Carolina: one with a low donor designation rate, one with a high rate, and one with an average rate. I selected Lexington County for the high rate, Sumter County for the average rate, and Allendale County for the low rate. Each county called for different recruitment strategies. A colleague who lived in Sumter recruited participants for me using social connections and word-of-mouth, and I used snowball sampling in Lexington to recruit participants. Allendale County proved far more difficult; over the course of several months, I contacted faculty from two local universities (I received no response from one, and another distributed flyers that received no response). I traveled to Allendale and provided assistance to a coalition representing a half dozen or more community advocacy groups in applying to a community transformation grant (I had served on the state's grant review committee the year before), and in exchange, the directors of these organizations distributed flyers around the community. I still did not receive a response from a single resident of Allendale.



As will be discussed later, groups in Sumter and Lexington did include non-donor participants, but my reason for attempting to engage Allendale was to recruit a group more predominantly non-donor to allow more open discussion of their thoughts about donation. Other than the age component (which was included as Donate Life and its partner OPO wished to target younger populations because “once a donor, you’re a donor for life,” as one OPO representative told me), the recruitment advertisement placed no other restrictions on donor status, gender, or ethnicity. The flyer did indicate that participants would receive a \$25 Visa gift card for their participation in a focus group of 60-90 minutes asking their reactions to organ donation advertising. The specificity of topic on these flyers could have had a deterrent effect on non-donor participation. In the end, to ensure adequate non-donor participation, I worked with health educator colleagues to recruit two small focus groups of non-donors from Richland County.

Although three focus groups of five participants were scheduled for each county, I did not recruit a comfortable buffer of additional participants. Groups had to be canceled or combined. The final makeup of groups is described below.

*Sumter County Group 1 - held at board room in Sumter County Museum*

Joaquin<sup>4</sup>: Latino male from California, raised in Guam, husband of Michelle and a father.

Michelle: female raised in Guam. Identifies as Pacific Islander. Wife of Joaquin and a mother. Officer in the Air Force, living at Shaw Air Force Base.

J.T.: male raised in Guam. Identifies as Pacific Islander. Husband of Amanda and expectant father. Officer in the Air Force, living at Shaw Air Force Base.

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<sup>4</sup> I have assigned pseudonyms for all participants to preserve their anonymity.

Amanda: female raised in Guam. Identifies as Pacific Islander. Wife of Nelson, expecting her first child. Officer in the Air Force, living at Shaw Air Force Base.

Sophie: female from Hawaii. Identifies as Filipino. Graduate student and married to Air Force officer, living at Shaw Air Force Base.

*Sumter County Group 2 - held at board room in Sumter County Museum*

Dave: white male from Kentucky. Husband of Alison. Enlisted in the Air Force, living in Sumter.

Alison: white female from Kentucky. Wife of Dave. Works in marketing and communications, living in Sumter.

Robert: African-American male from Chicago. Husband of Shelly. Enlisted in Air Force, living at Shaw.

Flora: female from Guam. Identifies as Pacific Islander. Stay-at-home mother and wife of Airman at Shaw.

Eileen: female from Hawaii. Identifies as Filipino. Stay-at-home mother and wife of Robert.

Nelson: African-American male from South Carolina. Husband of Shelly. Air Force officer, living at Shaw.

Shelly: female originally from California. Identifies as Pacific Islander. Wife of Nelson and expectant mother. Air Force officer, living at Shaw.

*Lexington 1 - held at Lexington County library*

Julie: white female originally from Buffalo, New York. Wife of Daniel. Biochemist, living in Chapin, SC.

Daniel: white male from France, raised in Pittsburgh. Husband of Julie. Computer engineer, living in Chapin, SC.

*Lexington 2 - held on USC campus*

Jamie: white female raised in Lexington County. Teacher and mother of two, living in West Columbia, SC.

David: white male raised in a military household, so no place he calls “home.” Husband of Emily. Pet store manager living in West Columbia, SC.

Emily: white female from Columbia, SC. Wife of David. History graduate student, living in West Columbia, SC.

*Lexington 3 - held in Lexington County library*

Sara: white female from Michigan. Wife of Brandon. Paralegal living in Lexington, SC.

Brandon: white male from Easley, SC. Husband of Sara. Engineer living in Lexington, SC.

Kate: white female from Columbia. Salesperson in music store living in West Columbia, SC.

*Richland 1 - held on USC campus*

Mallory: African-American female from Charleston. Graduate student living in Columbia, SC.

Shirley: African-American female from Columbia. Health promoter living in Columbia, SC.

*Richland 2 - held at Department of Health and Environmental Control*

Sherman: African-American male from South Carolina. Funeral director living in Columbia.

Stacy: African-American female from Columbia. Call center manager living in Columbia.

Tara: African-American female from Pittsburgh. Receptionist living in Columbia.

Upon arrival, participants received a copy of the statement of informed consent and a \$25 Visa gift card. After receiving permission to record, I read the statement of informed consent aloud, reminding participants that they were under no obligation to answer any question and could leave at any time while still receiving compensation. After acknowledging consent, I introduced the research in more detail.

Participants watched a series of ten videos ranging from thirty seconds to four minutes. After each video, I asked a semi-structured series of questions about their reactions to each video and encouraged participants to respond to each other as well as to my prompts. Before the first video, I asked participants about advertising in general to break the ice and learn some basic information about what each of them appreciated or despised about ads they had seen in the past.

The general, semi-structured order of questions was this:

General thoughts: what did you like or dislike about this video?

What do you believe the message was?

Do you agree with the message? Why or why not?

What did you think about the speaker? Did you connect with him/her?

(If video was religious): What are your thoughts about the use of religion in this video? Do you agree with the message?

Any other thoughts about the video?

I used these prompts if participants were not discussing the video or focusing too intently on production values (the font, color, camera shots, and so on). These questions provided a kind of neutral ground for the discussion of organ donation; most participants ended up discussing personal thoughts or experience with donation, and I asked follow-up questions, gauging the participants' responses to avoid asking questions they would not be comfortable discussing in front of a group<sup>5</sup>. Despite relatively few questions and only about ten minutes of video to watch, almost every focus group exceeded the 90 minute time limit, as participants discussed the videos and their thoughts with one another.

I transcribed each group in great detail, noting pauses and repairs in speech to provide sufficient detail to conduct conversation analysis on key excerpts. I used NVivo 10 and Dedoose (a cloud-based qualitative analysis software package) to code each transcript. I first open-coded the transcript to develop a codebook of common themes, then recoded to ensure consistency for analysis. The final codebook is in Appendix [#]. Transcripts were coded first for critical-interpretive analysis based around themes of

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<sup>5</sup> My desire for compelling ethnography had to be balanced with participants' rights to privacy.

embodiment and political-economy, then coded for video characteristics based around framing theory and treatment of message and speaker.

Key excerpts from these focus groups are presented in Chapters Four and Five, with context and discussion. I chose not to conduct a quantitative analysis of codes, as I believe the “raw” excerpts themselves provide the details to fill gaps missing in studies of organ donation communication. Although a study of statistical significance of particular codes would no doubt be illuminating in its own right, it would serve also to gloss over the details of personal experience that lead individuals to choose to register—or not to register—as donors. More can be learned by investigating individual voices than attempting to extrapolate and generalize to other populations.

I have also been a focus group participant and found a common strategy among focus group moderators to minimize the dominance of one voice or another and ensuring representation of diverse voices by following a fully structured schedule of questions. The question is read, the first participant is asked the question (with no follow-up), and then the moderator turns to the next participant and asks, “What about you?” Rinse and repeat until all participants have responded, then ask the next prewritten question (starting this time with the second participant) and begin the process anew.

This approach to qualitative research can be problematic. While a structured interview schedule can be used effectively, the rigidity of the format described above silences all voices in the room and discourages the rich discourse that follows conflict or agreement. It prevents a participant from continuing the thought of another and taking the conversation into deeper territory. It is within deviation—and yes, even dominant voices—that meaning is embedded. Even when one participant speaks their piece at

greater lengths than others within the group, the moderator should be able to elicit thoughts from more reserved participants without muzzling discourse. A moderator can encourage conflict without argument. The semi-structured approach I employ promotes a diversity of voices.

In the following three chapters, I will describe the results of this study and the answers to my underlying research questions.

## CHAPTER 3

### CONTENT ANALYSIS

#### 3.1 INTRODUCTION

As discussed in Chapter 1, there is a need to study not just discourse and attitudes surrounding organ donation messages, but the messages themselves. Scholars studying organ donation communication have tended to rely on a limited number of *a priori* frames—most typically, organ donation as “the gift of life” or as a “sacrifice” (Sque, Payne, and Macleod Clark 2006). No mention is made of how these frames are derived; none of these studies mention message creators or other source that could provide insight into the messages. It seems as though the presence of these frames is simply accepted without sourcing.

Certainly, “the gift of life” is a frame that appears valid, given that the national organization promoting donation is itself called “Donate Life.” But for all the studies that have puzzled at how positive reactions to certain messages do not yield increased registration rates, is it then possible that other message frames exist in the ether, potentially creating different, perhaps competing, interpretations of donation? In short, is it possible that OPOs are talking out of both sides of their mouths, as Sharp (2006) suggests?

More practically for the purposes of my research, a content analysis will provide me with a defensible sample of videos to show focus group participants. If I selected 10



videos out of 400, I could either select based on personal preference—ignoring the effect of message frames entirely, as my selections as a White, middle class organ donor are likely not universal—or select a sample entirely at random without stratification, running the risk of showing 10 videos similarly framed and missing out on other, perhaps competing messages promoted by OPOs. By conducting a content analysis and clustering videos based on the results, I can select videos that are distinctly framed and representative of a wide range of messages.

A challenge lay in finding a population of OPO-promoted videos. Not only are they relatively uncommon to see on TV, but because OPOs cover specific geographic regions, it is almost certain that they would target their messages differently. I would need the videos to be both easily accessible for viewing and representative of as large a swath of the U.S. as possible. Luckily, this is the 21st century.

Increasingly, non- and for-profit organizations are using “Web 2.0” communication resources to promote the mission of their organization. The term typically refers to recent Internet technologies that enable users to publish and share content, such as social networks, blogging tools, or video upload services like YouTube (Kamel Boulos and Wheeler 2007). Since its launch in 2005, YouTube has emerged as a powerful, user-driven platform for sharing content. According to the site, some 72 hours of content are uploaded to the site every minute and there are more than 800 million unique visitors per month (YouTube, n.d.). In line with other non- and for-profit organizations, OPOs often produce video content for YouTube and showcase this content prominently on their Web page. As YouTube has increasingly become a source of health information for the public

(Vance, Howe, and Dellavalle 2009), assessing its content and effectiveness is crucial to ensuring the success of future social marketing campaigns.

YouTube and other Web 2.0 technologies also offer new avenues for anthropologists studying meaning and interaction in today's global society. Michael Wesch, himself a one-time YouTube sensation, has written and lectured on the medium's potential for connectivity and self-reflection (2007). In a study of semiotics and YouTube, Betsy Rymes writes, "This process—recontextualization and incorporation into local communicative repertoires—occurs without YouTube, but YouTube is a remarkable medium because it makes this process visible to the analyst. Just as a photographer's developing fluid suddenly reveals a previously invisible image in the darkroom, the medium of YouTube reveals and accelerates (and extends globally) social processes that have, until now, been largely invisible to us as discourse analysts worried about micro and macro" (2012:225).

As Rymes notes, the advantage of YouTube as a medium of study lay in its capacity to document microcultural artifacts as they become dominant macrocultural touchstones, allowing the anthropologist to observe clearly—from the comfort of home—the changes those videos undertake over time. A single search for "organ donation" on YouTube retrieved over 87,000 videos at the time of writing, posted from dozens of countries and featuring thousands of different perspectives on the practice. Though a digital video may seem ephemeral (who *really* remembers the Soulja Boy video of which Rymes writes?), these videos date back years and YouTube serves as a time capsule, perfectly preserving these cultural artifacts for future study. One can undertake an in-depth ethnographic study of organ donation discourse without actually needing to meet

another person. As the first step of my study, I will apply framing theory within a critical-interpretive context to do just that.

Unlike other health messages, such as those promoting smoking cessation or wearing a helmet, organ donation communication can offer no tangible, life-saving benefits to the potential registrants, and for any societal benefit to be realized, the registrants themselves must first die. Donation messages are unique in that they must encourage their audiences to think about and prepare for their eventual deaths, not offer solutions to save their lives. An in-depth study of the strategic communication of organ donation messages that considers the models of framing described above will enhance detailed understanding of organ donation communication and the mechanisms that influence individuals' donation decisions.

This is not the first content analysis of organ donation messages. Scholars have also explored how the concept of organ donation is portrayed in the mass media. For example, Morgan and colleagues (2007) examined primetime, fictional television shows such as *Grey's Anatomy* and *Law and Order* and concluded that entertainment media promoted two dominant frames about organ donation: first, the "moral corruption of the powerful" that results in the murder of innocents to fuel the demand for organs, and second, that organ donors are selfless and good. Feeley and Vincent (2007) explored how organ donation was presented in newspapers, finding most articles were either positive or neutral about donation and frequently combined human interest stories and statistical messages. Quick, Kim, and Meyer (2009) looked at primetime TV news coverage of organ donation and found that donation received positive, but inadequate, representation. Finally, Tian (2010) used the coding categories of Feeley and Vincent (2007) and the

researcher-derived frames of Morgan, et al. (2007) to analyze YouTube videos with the key phrase “organ donation,” examining both message frames and audience frames of posted YouTube comments. Tian (2010) found an overwhelmingly positive portrayal of organ donation by both individuals and nonprofit organizations that contrasted with Morgan, et al.’s (2007) description of entertainment television’s portrayal.

Although Tian’s study provides important insight into the presence of specific frames in YouTube videos and user comments, it does not paint as vivid a picture of how OPOs frame pro-donation messages to encourage registration—what Hallahan, et al. (2007) call “strategic communication.” An in-depth study of organ donation messages as strategic communication that considers the models of framing described above could enhance detailed understanding of organ donation communication and the mechanisms by which it influences individuals’ donation decisions. As Tian notes, “positive audiences frames and ratings on organ donation videos on YouTube...did not necessarily translate into positive behavioral outcomes” (2010:244). A detailed differentiation of positive message frames, however, could help understand why not.

My work examines American OPOs’ framing of organ donation in greater detail to both understand how they craft messages to promote donation registration and allow me to select distinctly framed messages to elicit audience reaction and determine how culture affects the processing of those messages. The content analysis is a type of formative research, which—as Tanner and Friedman note—is an important step in developing effective social marketing (Tanner and Friedman 2011). It also provides a buffet of content from which I can serve my focus groups to examine donation discourse in the next two chapters.

The specific statistical methods I used are described in more detail in the previous chapter. Although one should always beware of anthropologists wielding statistics, I urge the qualitatively positioned reader to bear with me through the tables and figures that follow. Obtaining these results was necessary for me to confidently establish the message frames promoted by OPOs. These are the quantitative vegetables one must eat before he can enjoy his qualitative pudding.

### 3.2 VIDEO CHARACTERISTICS

First, I explored the characteristics of videos posted on YouTube by OPOs. Superficially, what are they, and who is in them? The frequencies of those characteristics are shown in Table 3.1.

Table 3.1 Frequencies of video characteristics

Variable	N	%
Speaker Characteristics		
Role: Recipient	122	32.4
Role: Donor family	82	21.8
Role: OPO representative	69	18.3
Role: Recipient family	48	12.7
Role: Healthcare professional	28	7.4
Role: Actor (scripted)	25	6.6
Role: Celebrity	21	5.6
Role: Transplant candidate	19	5
Role: Journalist	10	2.7
Role: Donor	8	2.1

Structure			
	Thematic/Narrative	304	80.6
	Episodic/Statistical	63	16.7
<hr/>			
Problem Definition			
	Topic: Life	275	72.9
	Topic: Death	181	48
	Topic: Giving	170	45.1
	Topic: Remembrance	116	30.8
	Topic: Waiting	134	35.5
	Topic: Gratitude	88	23.3
	Topic: Religion	59	15.6
	Topic: Hero	31	8.2
	Topic: Myths/misconceptions	30	8
	Topic: Obligation	30	8
	Topic: Brain death	19	5
	Topic: Disparities	6	1.6
	Topic: Sacrifice	3	0.8
<hr/>			
Treatment			
	“Humanize” donation	185	49.1
	Raise awareness/increase knowledge	132	35
	Chronicle event or function	24	6.4
	Other	23	6.1
	Provide tools/info for registration	13	3.4

The number of posted videos increased exponentially over the three years of the sample, which follows the generally explosive growth of YouTube content since its creation in 2005 (YouTube, n.d.). Despite that growth, the cumulative proportion of posted videos that were professionally produced remained constant throughout that time at about 50% (n=214). Figure 3.1 demonstrates this trend; it suggests that while OPOs are posting more content than ever, that content is not necessarily part of organized communication campaigns and may not share a consistent message with other videos.

Of the 377 videos included in the study, the number of views at time of data collection ranged from 1 to 24,341, with a fairly low median of 119.

### 3.3 SPEAKER CHARACTERISTICS

Males and females were equally likely to appear in the videos (56.8%, n=214 vs. 55.4%, n=209, respectively). Most videos featured White speakers, followed by African-Americans (21.2%, n=80), Latinos (9%, n=34), Asian-Americans (3.7%, n=14), and Native Americans (0.3%, n=1). More than three quarters of the videos featured adults young enough not to be identified as “older adults” by the coders (78.2%, n=295), while older adults were featured in only 12.2% (n=49) of the sample. 11.4% (n=43) of videos featured children or teenagers.

### 3.4 VIDEO FORMAT

PSAs comprised a third of all videos (33.4%, n=126), followed by formal interviews (26.8%, n=101) and informal interviews (21%, n=79). Other video types—news stories, chronicles of events or functions, press conferences, and other—were low in numbers and I excluded them from further analysis because, although posted by the OPOs on their YouTube channels, the messages are framed and developed by other

organizations and individuals, such as local news broadcasters or politicians, rather than by the OPO itself.

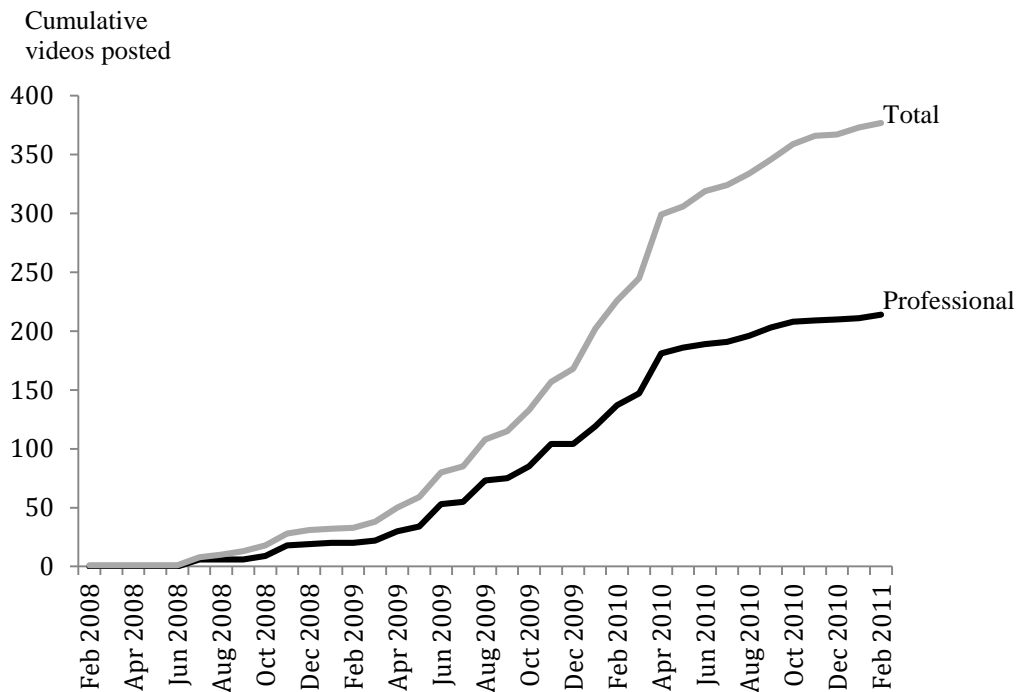


Figure 3.1 Total and professionally produced videos posted by organ procurement organizations, February 2008 to February 2011

The most common primary focus of the videos was “humanizing” donation (49.1%, n=185), followed by raising awareness of the need for organs or increasing knowledge of the donation process (35%, n=132) and explanations of how to register as an organ donor (rather than only a reference to a website or phone number; 3.4%, n=13)

### 3.5 FRAME ELEMENTS

Narrative messages greatly outnumbered statistical messages (80.6%, n=304 vs. 16.7%, n=63). “Life” was the most common frame element, appearing in 72.9% (n=275) of all videos. Death was the second most common frame element, appearing in 48%



(n=181) of all videos. Brain death was explicitly mentioned in just 19 videos (5%), only three of which were PSAs.

PCA provided a means for seeing how frame elements correlated with one another to form “factors” or, less abstractly, thematic frames. Factors with fewer than two variables were discarded from further analysis (Tabachnick and Fidell 2007). The results of the PCAs conducted on PSAs, informal interviews, and formal interviews are shown in Table 3.2 below.

Table 3.2 Obliquely rotated component loadings of public service announcements, informal interviews, and formal interviews

Public Service Announcements	Component	1	2
	Remembrance	.790	
	Death	.760	
	Brain Death	.666	
	Giving		.826
	Life		.628
	Gratitude		.685
	Eigenvalues	2.099	1.232
	Percentage of total variance	34.98	20.54
	Number of variables	3	3

Loadings=>.462, Overall KMO=.556

Informal Interviews	Component	1	2	3
	Religion	.862		
	Death	.647		

Brain Death		.789	
Remembrance		.688	
<hr/>			
Eigenvalues	1.92	10.08	
Percentage of total variance	32.08	18.03	
Number of variables	2	2	

Loadings=>.647, Overall KMO=.660

Formal Interviews	Component	1	2	3
<hr/>				
	Death	.829		
	Remembrance	.746		
	Brain Death	.588		
	Misconceptions		.785	
	Disparities		.653	
	Life		-.648	
	Religion			.715
	Giving			.632
	Obligation			.605
<hr/>				
	Eigenvalues	2.103	1.492	1.258
	Percentage of total variance	23.37	16.58	13.98
	Number of variables	3	3	3

Loadings=>.518, Overall KSA=.620

For PSAs, two frames emerged from the factor loadings: “remembering the dead” as reflected in themes remembrance, death, and brain death and “thank you for the gift of

life” as reflected in themes giving, life, and gratitude. Informal interviews showed two frames: a theme of religion and death and a theme of remembering those declared brain dead (donors). With formal interviews, as with PSAs, “Death” “Remembrance” and “Brain Death” loaded strongly onto a factor and will be known as “Remembering the dead.” Factor 2 had two strong loadings and an inverse loading and can be called “Myths, misconceptions, and concerns about equality.” The inverse (negative) loading of “Life” should not be assumed to be equivalent to a coding of “Death,” as the two elements were coded separately. Because of its two strong loadings, Factor 3 can be renamed “Giving is a holy act.”

K-means cluster analysis was conducted to see how, based on the identified thematic frames, videos formed groups along how strongly they correlated with elements of a frame. Table 3.3 shows these clusters for each of the three video types.

Table 3.3 Clustering of OPO-framed messages

Cluster	Size	Cluster Means for Frame	
		“Remembering the dead”	“Thank you for the gift of life”
1	3	4.248	-0.399
2	12	1.362	0.696
3	24	-0.434	-1.129
4	10	0.327	-0.280
5	29	-0.675	-0.179
6	26	-0.448	0.863
7	5	1.026	2.083
8	5	-0.918	2.011
9	12	0.728	-1.247
Overall R <sup>2</sup> =.903, CCC=5.845, Cross-validation error rate=1.59%			
Cluster	Size	Cluster Means for Frame	
		“Religion and death”	“Remembering those declared brain dead”
1	2	0.891	1.822
2	11	-0.143	-0.202

3	26	-0.637	-0.518
4	12	-0.504	-0.201
5	6	-0.01	0.114
6	11	0.309	0.127
7	4	0.67	0.126
8	7	0.175	-0.19
Overall $R^2=.793$ , CCC=7.910, Cross-validation error rate=0%			
Cluster Means for Frame			
		“Remembering the dead”	“Myths, misconceptions, and concerns about equality”
			“Giving is a holy act”
1	15	-0.492	0.431
2	1	0.733	0.94
3	14	0.454	0.533
4	17	1.008	0.903
5	7	-0.624	0.443
6	19	1.126	0.419
7	13	0.487	0.279
8	10	0.529	0.477
9	5	-0.534	0.217
Overall $R^2=.839$ , CCC=2.426, Cross-validation error rate=19.8%			

Size represents the number of videos contained in each cluster. The cluster means reflect how strongly the coding of the videos within represented that framing. A cluster with a high mean for “Thank you for the gift of life,” for example, suggests the videos within were framed with that message.

To ensure a thorough investigation—and not coincidentally, because peer reviewers suggested it—I conducted a post hoc analysis to investigate significant effects between cluster assignment (framing) and proxy behavioral outcomes, the number of views and the donor designation rate of each state’s registry (Donate Life America 2013). Although I have discussed before the danger of using proxy measures for donation registration behavior—namely, that none of these proxy measures ever seems to adequately predict actual outcomes—such an analysis could produce a crude estimate of

likability or effectiveness prior to conducting the focus group component of my research. The number of views were found to be non-normally distributed, so I used a logarithmic transformation before performing a one-way analysis of variance (ANOVA). The mean number of views did not differ significantly across clusters for PSAs [ $F(8,125)=1.6$ ,  $p=0.111$ ], informal interviews [ $F(7,78)=0.5$ ,  $p=0.831$ ], or formal interviews [ $F(8,100)=1.17$ ,  $p=0.323$ ]. Using ANOVAs, no significant effects were found between cluster assignment and donor designation rates for PSAs [ $F(8,125)=2.00$ ,  $p=0.053$ ], informal interviews [ $F(7,78)=1.20$ ,  $p=0.315$ ], or formal interviews [ $F(8,100)=1.82$ ,  $p=0.083$ ].

### 3.6 DISCUSSION

Using a combination of statistical tests, I was able to deductively identify the message frames used by OPOs to promote organ donation on their YouTube channels, including the “who” (speaker characteristics), the “what” (thematic factors), and the “how” (episodic or narrative structure). Although these frames are by no means exhaustive given the dynamism and diversity of the Web 2.0 environment, they provide a broad inventory of past and current organ donation messages and an empirical basis for future conversations about organ donation messaging. Additionally, these methods provide further evidence for the use of cluster analysis to investigate message frames as proposed by Matthes and Kohring (2008).

It is important to note the differences among video types and message framing. Tian (2010) found that 96% of the YouTube videos analyzed had “positive” framing, in that they were supportive of organ donation. These themes appeared in the present study as well, but in other forms; Tian’s frame of “donors are good people” is reflected in

“remembering the dead,” his frame of “personal experience” is reflected in frames such as “thank you for the gift of life,” and his frame of “it is important to donate organs because of organ shortage” can be seen in videos featuring the “waiting/disease/need” theme I coded (although that element did not load significantly onto a frame). Two of Tian’s negative frames—“corruption of the medical system” and “rich people can buy anything” appeared in videos addressing myths and misconceptions about donation.

Because all videos analyzed in the present study were posted by OPOs and therefore encouraging of donation, the definition of positive and negative framing differs from Tian (2010); positive frames refer here to those emphasizing gains and negative frames refer to those emphasizing losses. Positive frames, such as “thank you for the gift of life” or “giving is a holy act” as found in PSAs and formal interviews, did not emerge from an analysis of informal interviews, which tended to be brief, unedited, and “man-on-the-street” style. This suggests that the frames promoted by OPOs through the PSAs they produce—which were overwhelming professionally crafted and edited—differ significantly from those of the volunteers, donor families, and recipients interviewed extemporaneously.

From a strategic communication perspective, this appears poorly planned; OPOs are conveying many different messages instead of crafting YouTube campaigns focusing on one or a few key, targeted messages. Interestingly, concepts such as brain death—which features prominently in informal interviews—was not present in the message frames promoted in PSAs. It is possible that this omission is itself a strategic decision to avoid mentions of a condition that remains controversial even among medical professionals (Kim, Fisher, and Elliott 2006; Lock 2002; Truog and Robinson 2003).

Addressing myths, misconceptions, and concerns about equality was a significant frame for formal interviews, but perhaps because of their typically brief format, it was not a common frame for PSAs.

As more than half of OPO-produced PSAs had a primary focus coded as “raise awareness about the need for organs and tissues,” attribute framing is one appropriate model by which to analyze how OPOs craft organ donation messages. Levin and colleagues (1998) note that messages designed to increase the salience of an object (e.g. organ donation) or its characteristics work best when positive attributes are emphasized over negative attributes and when individuals assume there is no risk involved in making their decision. Both positive framing (“thank you for the gift of life”) and negative framing (“remembering the dead”) of organ donation are strongly represented in PSAs. Based on the influence of each frame on clustering, positive and negative attribute frames were equally represented.

As Tian notes, videos receiving high ratings or comments indicating approval of organ donation “did not necessarily translate into positive behavioral outcomes” (2010:244). A detailed differentiation of message frames, as found in the present study, however, helps explain this finding; not all pro-donation messages are framed similarly, and as Hallahan notes, message frames affect audiences’ cognitive responses and—consequently—their actions. Although a post hoc analysis revealed no significant interactions between cluster assignment and number of views for any of the video types, this is an imperfect measure of a frame’s effectiveness; YouTube views are moving targets changing by the hour, and differences among OPOs including the populations they serve and how aggressively they promote the use of their YouTube channels may

influence view counts more than framing. Likewise, any number of factors external to message frames can influence donor designation rates; given the low number of YouTube views compared to state populations, the immediate effects of these videos on behaviors and attitudes is not so easily seen.

Other models of framing can provide insight as well. Framing of actions and framing of risky choices are lenses through which one can explore organ donation PSAs. Some messages—particularly those that put a human face on donation and transplantation through personal narratives—may operate under cognitive schemata that encourage action to avoid losses rather than obtain gains. Under this assumption, a video of a 15-year-old girl on dialysis (Kayla on Dialysis 2008) could be more effective than an 11-year-old girl saved by a transplant (Priscilla 2009), as it emphasizes potential losses—albeit from a societal rather than individual perspective—over the realized gains of a life already saved. I wonder, but cannot assert, whether the assumptions of these models of framing are applicable to organ donation and whether an individual’s preconceived notions and experiences with donation (i.e., whether they consider it a risky choice or no risk at all) affect their cognitive processing of message frames.

The distinct factor loadings for “thanks for the gift of life” and “remembering the dead” mean that these two frames typically do not appear in the same messages. This result suggests that Sharp’s (2006) finding that OPOs promote different messages about the meaning of organs is correct. The disorganized and untargeted nature of OPO YouTube channels, however, challenges Sharp’s contention that OPOs work to keep these messages separated by audience (potential registrant versus donor family) to minimize the presence of conflicting messages.



I never saw the Hollywood-promoted frame of greedy doctors murdering patients to harvest organs, as described by Morgan (2007). Although the “gift of life” theme appeared in PSAs, a finding in line with previous work (Sharp 2006; Siminoff and Chillag 1999; Sque, Payne, and Macleod Clark 2006), the “gruesome” theme of sacrifice as suggested by Sque and colleagues (2006) appeared in only three videos—one formal interview and two news stories. Second, the “spare parts” frame described by Schweda and Schicktanz (2009) and Sharp (2006)—one in which organs possess no meaning beyond masses of flesh and blood—did not appear in any PSA. This suggests that although OPOs may promote competing messages—one of life and one of death—they are not *contradictory* messages. Based on her ethnographic research, Sharp (2006) explained that OPOs target potential registrants with messages that separate meaning and cultural significance from organs while comforting donor families with messages that their loved one lives on in his donated organs. My findings are consistent with Sharp’s (2006) qualitative research. Although some informal interview participants made statements such as “you won’t need them when you’re gone,” this frame is conspicuously absent from PSAs. The significance of donation to recipients and donor families, however, is on full display in these YouTube videos. This suggests that OPOs may have abandoned contradictory messages, perhaps finding that highlighting rather than minimizing the cultural or symbolic meanings of organs may be more effective at convincing a skeptical public to register as organ donors.

The potential of YouTube and other social media sites as communication channels for health messaging is promising but could be problematic for reasons such as disparities in access (Chou et al. 2009) and the unregulated spread of messages

conflicting with the goals of public health (Kim, Paek, and Lynn 2010). There is little question as to why so many OPOs rely on the site for messaging: it is free and easy to use for both sender and receiver, reflective of a paradigm shift to social media within health communication, and allows for interaction and feedback through video responses, comments, ratings, and sharing in ways that traditional broadcast media cannot (Thackeray et al. 2008).

Based on the findings of this study, OPOs' YouTube channels appear to have two major pitfalls. First, there is the issue of YouTube as a self-selected channel. Even the most-viewed video of the study sample, "Steve's Organ Donation Story – The Circle of Life" (Donate Life Illinois 2008), topped out at 24,341 views. For comparison, a crudely animated cat dressed as a pop tart flying through space has, at the time of this writing, 79,356,868 views (Nyan Cat [original] 2011). Lacking the elusive and inimitable attribute of virality, OPO donation videos may be available for all to view, but practically invisible.

The second pitfall of the use of YouTube as a channel for organ donation messaging is the apparent lack of editorial oversight on the part of the channel owners. As the variety of video types, production values, and foci attest, the OPO channels do not appear to be cohesive campaigns developed by communications professionals. For example, among the 21 uploads of the Donate Life Northwest YouTube channel, one can find an 18 minute, professionally-produced informational video about donation; a shaky, 13 second video of vampire movie *Twilight* actor Robert Pattinson's head pasted on a cardboard cutout at the organization's office; touching and heart-wrenching stories from donor families, recipients, and transplant candidates; and 75 seconds of a camera panning

across rows of cupcakes baked for a fundraiser (Donate Life Northwest 2010; 2010).

These poorly-curated channels suggest some OPOs may not include YouTube as part of a comprehensive strategic communication plan.

Despite the promise of quantitative content analysis for valid and reliable anthropological measurement, my methods nevertheless have some limitations. Although the results demonstrate a modestly acceptable fit for k-means cluster analysis, this is an appropriate but imperfect data mining method for binary variables (Brusco 2002; Dimitriadou, Dolničar, and Weingessel 2002). Future research should examine the use of experimental data reduction and clustering algorithms that correct for binary and categorical data (Huang 1998). Additionally, given Entman's (1993) call to shore up the "fractured paradigm" of framing theory, this study deviates from his framing formula of problem definition, causal attribution, moral evaluation, and treatment by coding not for causal attribution and moral evaluation but speakers (i.e. frame actor) and argument structure (i.e. statistical and/or narrative). Keeping coded variables simple and broad to minimize coder schemata may have glossed over important distinctions that could more fully integrate causal attribution and moral evaluation into the study. For example, a video mentioning religion to imply a moral obligation and a video in which a speaker describes a deceased donor as an angel sent by God are both coded under the ambiguous variable "religion," although the connotations are quite different. Although the presence or absence of topic variables should remain the building blocks of inductively identified frames, future research that partitions these variables may provide additional detail into the ways OPOs frame organ donation messages.

### 3.7 IMPLICATIONS

The results of this formative study have implications for Web 2.0 platforms, health communication researchers, OPOs, and other anthropologists. Although Web 2.0 platforms such as YouTube offer unprecedented reach and interactivity to health communicators, this study found evidence that many channels lack editorial oversight, and that messages of vastly different format, production quality, and framing compete for attention without regard for audience segmentation or strategic communication planning. The frames identified and the clusters of videos provide insight into the way OPOs communicate strategically (or not) to promote organ donation to the public, which not only opens up new avenues of research for scholars, but offers an inventory of message frames that OPOs can look to for future campaigns.

This approach to content analysis can minimize researcher bias and provide valid, statistically-derived frames from a selected set of variables. Identifying frames across videos is a means of elucidating intersubjective meaning, even in the absence of access to those message creators. One can find cultural patterns by asking questions of hundreds of messages, just as Dressler investigated cultural consonance by asking questions of family units. The most obvious (and valid) criticism of such an approach, and perhaps framing theory itself, is that I am inferring meaning and cultural significance without engaging members of the culture itself—a modern day armchair anthropology. I am speaking to the meaning of organ donation as understood by OPOs without directly engaging OPOs in that conversation. Yet this content analysis, I argue, is no less anthropologically sound than any other study of material culture. Heider (1988) comments on meaning and culture by analyzing *Rashomon*, but of course does not speak for Kurosawa. I comment on

meaning and culture by analyzing 453 OPO-produced videos. In the following chapters, I examine those symbols by shifting my perspective and methods to that of individual donors and non-donors. I will set the message frames I discovered against a context of political-economy that reveals how meaning operates within culture, and how it changes as it is processed by the individual.

## CHAPTER 4

### EFFECTIVENESS OF FRAMES

The unspoken advantage of ethnographic research in contrast to other fields—namely, laboratory sciences—is that the anthropologist need not *necessarily* formulate a hypothesis in advance of his research. Grounding one's theory in data conveniently enables one to reduce researcher bias and allows themes to emerge dynamically. Nevertheless, a review of existing literature would lead one to form these assumptions about effective organ donation framing:

1. Death would not be mentioned nor implied. Positive framing of donation would prove more effective than negative framing, following Levin, et al (1998), and by avoiding mention of death, OPOs need not frame donation behavior as a risky choice at all and avoid the leap to the gruesome that potential registrants weigh in their decision making process (Sque, Payne, and Macleod Clark 2006).
2. Community would be stressed over individual need (Jacob Arriola, Perryman, and Doldren 2005; Callender and Washington 1997; Etzioni 2003)
3. Narrative would be emphasized rather than statistics. Feeley and colleagues (2006b) found that narratives were more effective than statistics in designing organ donation messages. Anthropologists, likewise, have found the narrative to be a powerful tool in ethnographic witnessing (Englund 2006). As in Josef Stalin's famous (though perhaps apocryphal) quote, "The death of a single man is a tragedy. The death of millions is a statistic." A focus on the story of a real

person (such as an organ recipient), one may conclude, would be more effective than spouting numbers in need.

One may also assume that a video meeting these three criteria would somehow supersede the cultural macrostructure governing individual interpretations of videos (Shoemaker and Reese 1996) and could provide the core message frame of a “one-size-fits-all” campaign that would greatly improve cash-strapped OPOs’ ability to effectively motivate a large, diverse target audience without the need for expensive, multifaceted campaigns required for true audience segmentation. As it turns out, one would be wrong in that assumption, as the focus groups described this chapter will attest. A more thorough application of framing theory within a critical-interpretive context will, however, provide insight into the schemata at play in the processing of organ donation messages and suggest frame elements that are more or less effective in marketing organ donation registration. In this chapter, I test three hypotheses based on four models of framing suggested by Hallahan (1999) and described in communication research.

The first model is the framing of *situations*, which anthropologists and other social researchers use to examine how reality is constructed through language, discourse, and interaction, forming an interpretive schema as Goffman (1986) defines it. While such broader discussion of the creation of cultural systems is important, and the creation and perpetuation of cultural constructs is discussed in greater detail in the next chapter, other models of framing proposed by mass communication research can illustrate the processes through which messages are created by communicators and elucidate the way these frames are processed by the individual. One can use these applications of framing theory within a critical-interpretive context to better understand the role culture plays in message

interpretation, building up—if you will—to the overall construction of discourse and reality suggested by the framing of situations.

*Attribute framing* or “product positioning” suggests that messages seeking to increase awareness or salience of an issue or product— in this case, the need for organs—are more effective when they are framed positively—such as “the gift of life”—than negatively—such as noting those who died waiting for an organ transplant. Conversely, Kahneman and Tversky (2000) note that individuals are more likely to undertake risky *choices* when outcomes are framed in terms of avoiding losses rather than obtaining gains. Organ donation registration could be considered a “risky” choice, as noted in studies finding a mistrust of the medical system among individuals or as promoted by the media (Callender and Miles 2001; Morgan et al. 2007). OPOs are tasked with framing organ donation in a way that encourages the risky course of action. For example, framing organ donation in terms of the lives that are lost for lack of transplantable organs may be an effective means of encouraging a wary individual, according to Kahneman and Tversky’s model.

When considering the *framing of actions* model, “...the concern is how to frame actions necessary to achieve compliance with a desired goal” (Hallahan 1999:215). In terms of organ donation communication, do OPOs frame organ donation in terms of saving a life (positive) or preventing a death (negative)? Hallahan notes that, similar to framing risky choices, negative framing is more persuasive than positive when audiences are engaged in effortful processing, but that positively-framed messages may be more persuasive with less detailed cognitive processing (Smith and Petty 1996).



Finally, the *issues* framing model may help guide investigation into how OPOs refute negative arguments to organ donation, such as religious opposition or arguments about the inequity of donation and transplantation. For example, a PSA stating that most major religions support donation uses an issues frame to persuade viewers. Hallahan defines an issue as “a dispute between two or more parties” (Hallahan 1999:217), and Best (1995) describes the use of “claims makers” to “typify” that issue; that is, to provide rhetorical, frequently anecdotal examples that illustrate the claims maker’s argument and persuade audiences of that side of the issue.

Hallahan describes other models of framing in addition to those described above: responsibility framing, in which an argument is made to attribute responsibility, credit, or blame, for an effect or occurrence (examples abound in political rhetoric) and the framing of news, which models how stories are portrayed in the news media. While both could have applications for organ donation communication, they are not relevant to the present study, because I am examining frames produced by OPOs (not the media) in the form of PSAs, and my experiences conducting the content analysis did not find that PSAs were casting responsibility for an issue (such as an organ shortage).

The cluster analysis described in the previous chapter provided message frames illustrating aspects proposed by each of these four models. In this chapter, I use four of Hallahan’s models (attributes, actions, risky choices, and issue) to test the following three hypotheses:

1. Attribute and action framing: PSAs using positively framed messages about organ donation (e.g. “thank you for the gift of life”) will be more effective than negatively framed messages (e.g. “remembering the dead”).

2. Risky choices: If organ donation is considered a risky choice (particularly among non-donors), frames emphasizing avoiding losses (e.g. “these people will die without organs”) will be more effective than positive gains (e.g. “my life was saved by an organ transplant”)

3. Issues: When presenting arguments dispelling misconceptions about organ donation, expert claim makers will be more effective speakers than nonexperts.

This being a qualitative study, my definition of an “effective” video is one that has an overall positive reception across focus group participants. I am not using proxy measures of behavioral change to suggest that “thank you for the gift of life” will yield increased donation registration rates over “remembering the dead”; nevertheless, the findings may provide a useful guide for future OPO marketing campaigns. If a majority of participants loved “thank you for the gift of life” and despised “remembering the dead,” then it may be a good indication of how messages should be framed to increase the receptivity of audiences. The message, of course, is only one part of the equation. In this chapter I will also examine reactions to characteristics of communicators themselves to determine if attributes such as age, race, and gender impact audience reactions to the message frame.

#### 4.1 OVERVIEW OF FOCUS GROUPS

The first focus groups I conducted were in Sumter County. I was unfamiliar with the area and worried about finding a convenient location to conduct focus groups on the weekend, as the library had limited hours. I learned that the county museum had a board room that was rented out for community groups to hold meetings for a nominal fee and,

as it was convenient to both the nearby Air Force base and town, would work well for holding the groups.

The first group included five participants—two males and three females. The most common themes to emerge during the conversation were generally negative; participants overall did not really care for most of the videos, but the conversation was dominated by Joaquin, an airman living at Shaw Air Force base. Though personable and exhibiting a great sense of humor, Joaquin injected a dose of honest negativity throughout the group. It was refreshing. As this was the first focus group I had conducted for this study, I was nervous and tinkering with the structure and schedule of questions, and I believe my initial uneasiness contributed to the group's overall reticence during the first minutes of the group. Joaquin, however, spoke his mind from the very first, and I believe his forthrightness helped bring the rest of the group into the conversation.

The dynamic of the group, though energetic by the end, was one of conflict. Joaquin was a non-donor, which he revealed directly later in the group but alluded to in his reactions to videos early, while the rest of the group were registered donors. If a participant indicated they liked a video, Joaquin would pipe up and question it and end up convincing others in the group to state their dislike of it as well. The overarching theme was one of organ donation as political economy: “mistrust” and “inequality” were two of the most common codes, as was “dislike video.” These themes and Joaquin's story are discussed in detail in the next chapter.

The second Sumter County group was the largest of the study, as two last-minute cancellations led me to combine two smaller groups into one larger one. This created an uncomfortable dynamic at first that reminded me perhaps of an engagement party in

which two distinct groups of long-time friends must interact for the first time. Female voices dominated in this group while the males were more reserved. Unlike the first Sumter group, discourse, though at times personal, did not revolve around the body politic. Instead, the conversation revolved around qualities of the videos themselves. The most common theme was positivity about videos' messages, though participants also did not tend to like most of the videos overall. One participant, Alicia, came from a marketing background and, though she did not necessarily dominate the conversation, she provided input from the perspective of the expert, pointing out features of each video that were or were not effective.

That thread—one of academic detachment—was carried throughout all three groups in Lexington County, each of which included only pro-donation voices. The first group included a married couple, David and Emily. Despite overall agreement, David used the group as an opportunity to provoke arguments with Emily, prompting Jamie to attempt to assume the role of peacemaker. Although most of the discussion was around the qualities of the videos themselves, rather than the political economy of donation, themes of mistrust were echoed throughout Emily's discourse, as she felt most of the videos were manipulative. Negative themes—disliking the video, speaker, and message—were most common, although Jamie took a much softer approach than David or Emily, expressing her occasionally contrarian opinion in which she liked a video or message that the others disliked by enveloping it in academic detachment rather than bluntly disagreeing. This group, after hours on a weekday, was held in a seminar room on the nearby university campus.

The second and third focus groups were held in the Lexington County Library. The first of these groups was a much smaller group than anticipated, as two registered participants failed to show, leaving me with one married couple. This led to a fascinating and (I must admit) darkly entertaining dynamic. Julie began the group by asserting that they would certainly agree on everything. Then the two of them spent the next 90 minutes attempting to disprove that statement. As each of them were exceptionally loquacious, they would self-moderate, arguing about whose turn it was to expound upon their opinion after giving lengthy, frequently academic answers. They were the only group that was overwhelmingly positive about each video; even those they did not appear to care for, they would phrase in terms of how it would be effective for others.

The third Lexington group included three participants (one additional participant was called into work at the last minute)—a married couple and one of their friends. The dynamic was enthusiastic, mostly free of conflict, and overwhelmingly negative. Brandon and his friend Kate would riff on each other's jokes about each video, while Sara would jump in to restate the group's opinions in a somewhat nicer light. As with the other two Lexington groups, themes emerging from the discourse tended toward a discussion of the qualities of each video rather than deeper themes about organ donation. There was, however, a long discussion of the use of religion, which is discussed in more detail in the next chapter.

Although I attempted to recruit participants in Allendale County to represent voices of a community ranking among the lowest in the state (and country) in donor designation rates, I was unsuccessful. To ensure adequate representation of non-donor voices, I did a targeted recruitment in Richland County, yielding two groups. The first of

these groups included three non-donors, all of whom were coworkers within the health field, which yielded a lively and earnest discussion. Although qualities of the videos themselves were discussed, there was a much greater focus on themes of embodiment—the disfigurement of the physical body, the role of race and religion and the body as social symbol, and the body politic. The most common theme was that of mistrust of the medical establishment, which will be discussed in more detail in the next chapter.

#### 4.2 MODELS OF FRAMING

Although these groups were not scientifically sampled, they nevertheless provide a diverse group of voices capable of commenting on the effectiveness of different message frames. Simply listing which videos were liked, which were not liked, by whom, and why, would not necessarily be helpful in moving donation framing forward. Reactions to each of these videos across and within focus groups was, predictably, mixed. There was no one video that was universally loved, nor one that was universally hated. The favorite of one participant would, inevitably, be the least favorite of another. Reasons to like or dislike a video included essentially all possible characteristics of the video, from its production values to the forcefulness of its speakers to whether or not a participant found a video's attempt at humor funny or forced. All this proves is the concept of market segmentation. You can't please all of the people all of the time, which is not a particularly groundbreaking conclusion. Yet when limiting an analysis to a more detailed case study of three of the ten videos, set against the broader context of all videos viewed, patterns emerge. From these patterns, one can draw inferences about the effectiveness of certain frame elements. Situating these preferences within a critical-

interpretive context reveals problems with commonly held assumptions about message framing, and begins to elucidate the role culture plays in interpretation of messages.

As I described in Chapter 2, the content analysis yielded nine distinct video clusters. I selected one video from each of six clusters; one cluster consisted of only two videos, both of which were longer than 50 minutes (the length of the video meant multiple frames were present, thereby clustering the videos as outliers) and therefore excluded, and the other two clusters comprised compilations of multiple ads appearing in other clusters. I added four additional videos to the selection to make an even ten. The transcripts of each video are included in Appendix A.

#### *Charles Tillman – Why You Should Be an Organ Donor*

In this video, Charles Tillman—a professional football player—describes how his three-year-old daughter received a lifesaving heart transplant. It frames donation positively and with “thank you for the gift of life” and uses personal narrative rather than statistics. I included this video because it featured a celebrity spokesperson, and I wanted to know if this element would affect audience responses.

#### *Organ Donor Myths – Religion*

A Vice President of Operations at an OPO responds to a posed question: is it true that religion opposes organ donation? She suggests that all major religions support donation, but if one has questions, one should ask one’s clergy.

#### *Every 11 Minutes*

This video features only graphics with narration. Signatures of different people zoom in to form the number “11” while a narrator notes that every 11 minutes, a name is added to the transplant waiting list, and many will die waiting for a transplant. It frames

donation negatively, using “remembering the dead.” It also uses statistics rather than narrative. I included this video to see specifically if Every 11 Minutes, a South Carolina campaign, was effective.

*Steve’s Organ Donation Video – The Circle of Life*

Steve affectionately describes Kerry, the donor of his double-lung transplant, then describes how his life has improved dramatically since receiving his transplant. This video frames donation with “thank you for the gift of life” and with “remembering the dead.”

*Donate Life New England – The Givers*

A narrator emphasizes the role of community and giving while an animated ribbon zooms across pictures of community service. This video includes almost no explicit mention of donation and includes neither narrative nor statistics.

*Don’t Let another Chair Go Empty – Dana and Hank*

Dana and Hank are elderly organ recipients encouraging donation registration. It is framed somewhat around “thank you for the gift of life” but more weakly than other videos because of an overall lack of mention of gratitude.

*Taxi Series 5*

I selected this video to see how focus groups would react to scripted actors instead of “real people”—which was rare in PSAs—and also how a video framed around “myths and misconceptions” would play to audiences. In this video, “Craig” enters a taxi emblazoned with pro-donation stickers and tells his driver that he’s uneasy about hospitals because he heard that they will let one die if he is an organ donor. The driver,



“Leah” challenges that logic, her passenger recognizes the absurdity of that thought, and the two drive off.

### *Tyler*

Tyler is a teenage boy who received a bone and tissue transplant as a child after losing part of his leg to cancer treatment. The video features him talking briefly about his injury and explaining that he is a normal teenager today because of his transplant, illustrating this with shots of him playing golf. The video is framed around “thank you for the gift of life” but does not mention his donor.

### *National Donor Sabbath*

Bible verses flash across the screen drawing comparisons between organ donation and Christianity. The video concludes with quotes from recipients and donor families honoring donors. The video is framed around “remembering the dead,” and I included it because of its very explicit use of religion as an element.

### *Mascots on a Mission – Training Day*

Part of a month-long campaign, this video features a drill sergeant impersonator yelling at a group of people in mascot costumes (a heart, another organ of some kind, a bumblebee, and a dragon) to get them ready to promote donation. He is rattling off facts and statistics about donation, and the video attempts to use humor to drive its message. It is not framed by “thank you for the gift of life” or “remembering the dead,” relying instead upon elements of need coupled with statistical structure.

## 4.3 ATTRIBUTE FRAMING

One video testing the effectiveness of positive framing was “Steve’s Organ Donation Video” which had, at the time of writing, the greatest number of views of any

of the videos reviewed as part of this study. Although production values were high, the video was likely not broadcast using traditional media; at three minutes long, it would have cost Donate Life Illinois a fortune for a single airing. Perhaps it was played for audiences at donation memorials, shared widely as part of a social media campaign, or broadcast to schools. For this study, the original purpose of the video is immaterial; what matters is reaction to its content.

The images in the video are striking. Steve holds aloft a negative picture of his donor, Kerry, such that the sun shining through it illuminates her face. A shift from black and white to vibrant colors marks Steve's transition from illness to health resulting from his double lung transplant. He is shown in extreme close-up, a somewhat uncomfortable parallel to his deeply personal story.

At its core, Steve's video is a perfect illustration of both of the two dominant frames for public service announcements: "remembering the dead," as Steve spends the first segment of the spot describing Kerry as though he knew her personally, and "thank you for the gift of life" as Steve expresses his boundless gratitude to Kerry for his ability to breathe, walk, and live. The video is also a good example of a personal narrative.

Reaction to this video were mostly positive, as respondents liked both him and the framing of the message. The narrative structure of the video resonated well with most participants, donor and non-donor alike. In the following excerpt from Lexington, donor Julie sums it up well:

Julie: My only criticism of that video is that it's too long as a commercial to I guess keep people's attention um but I think that the message was really powerful that's one person's really powerful story and it's painted as a realistic portrayal of

what it is, I mean I know it was maybe a little much holding up her picture and stuff which is touching but I don't know if everyone does that but um you know someone had to die for him to get those lungs and that's hard but you know if you look at it as really is a gift to someone else to help them live, I don't know I think that's a powerful personal message. If they could shorten it and include some more statistics such as the eleven thing um I think that that would really pack a powerful punch um particularly if it was a-a public figure too that would be like a triple whammy h h h but I thought that was a really emotionally powerful message, I like it.<sup>6</sup>

Despite the overall positivity toward the video and message, it nevertheless sparked an interesting line of discourse in several groups. Steve's story elicited an expectation from respondents that organ recipients *prove* their sickness.

Alison: Yeah that was a good one. I mean you could tell it was-I mean kind of like the first one you know it was a real person talking about their real experience cause he definitely did not have a born for TV voice [laughter]

Dave: No, yeah.

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<sup>6</sup> Note that throughout this dissertation, I present focus group dialogue using a pseudo-Jeffersonian transcription style. Although I do not indicate inflection or length of pauses, I have attempted to keep breaks, self-repairs, and pauses within the text. I believe such transcription not only adds verisimilitude to the conversation, but preserves some semblance of the deeper meanings present in talk-in interaction. I have, however, used standard English spellings of utterances to eliminate "eye dialect" and prevent reader interpretations of speakers' individual dialects as less educated or somehow distracting from the meaning of their words. As such, I have also not excised my own stumbles, repairs, and utterances from the text.

Alison: But I mean that-that made it effective especially cause it was lungs I think and that he can talk to you so clearly without you know-telling his own story without you know he's not coughing, he's not rasping,

Dave: Yeah no shortness of breath no coughing or anything like that-

Alison: yeah it's a part of his story so that was good

Dave: It's the fact that he says you know I got both of my lungs and hear how clearly I can speak now and he never comes straight out and says that but you definitely hear it so.

In the next excerpt, J.T.—who has so far remained fairly silent throughout the conversation—speaks up to expand on the group's murmured appreciation of the video, in that it shows the positive outcome of donation. His wife Amanda adds that seeing evidence of his illness proves Steve's story.

Me: So a lot of you said you liked it, um, what are some of the reasons why you liked it?

J.T.: Cause you actually got to see somebody who got the effects of organ donation

Joaquin: Yeah and described the person and then you know

J.T.: Yeah like [game?] did [cough] uh huh

Michelle: And gave the story between both of them

J.T.: Yeah pretty much the impact of don-donating your organs

Amanda: mmhmm

J.T.: And you can tell it's a very honest cause it said you know that four uh four  
yeah

Joaquin: Four [?] or uh turned down, you know

Me: Yeah

Amanda: And then he showed also their pictures from the past when he was in a  
wheelchair

Joaquin: Yeah

Amanda: He had the oxygen tank right in front of him

Sophie: mmhmm

J.T.: 'S a lot of proof and you know...Honest stats

In the next exchange, even avowed donors Daniel and Julie discuss the  
importance of demonstrating illness to drive home the point of Steve's story.

Daniel: h h h um yeah so you know it-he-he tells-he tells how his life was  
improved or how his life was beforehand in that part of the video where he was  
talking about his-like before that um there's not enough visuals so I think it's-I  
don't think it's enough to say you need to- if you're gonna go there and talk about  
that then there should be more than just the one picture of him with his family um  
not-I don't-I don't mean to condescend or whatever but um I feel like more visuals  
of how life was more difficult and that's why I feel like a video i-if-if you could  
uh if there was a candidate out there that's willing to have their whole-the whole  
procedure documented-like if you hear someone-if you know someone or if you  
find someone on the-one the waiting list and if you can document their lives now

um like their hardships and all that and then um document the whole procedure the waiting the procedure and the aftermath and then the long term after that and then somehow combine it into um into a-a like thirty forty whatever time you have for a commercial I think that's key because you have all that-all those visuals people could-you know a lot of people could believe by seeing instead of you know telling them so if they can see this is how they were living they know exactly-again I think it goes to the details they can see all the details of how that person's life was improved instead of saying you know I can go up the stairs but now I can and you can see just how he's going up the stairs you know he's running really fast and he can-he's not even like winded versus you know I can go up the stairs and I'm smiling at the end, you know seeing provides all these details.

Julie: I agree with you I don't think that it's...feasible to track someone's entire illness and wait for an organ donor to come up and then to find a match and then go through the process and then afterwards, I don't think it's possible to do that in thirty seconds, but I agree with you that some kind of video clip of this guy on a ventilator in a bed and not be able to do anything cause he has ten percent lung capacity, I think that would be a good like hey this was my life, this hospital bed hooked up to this machine doing nothing but waiting so I think that a stark visual like that not necessarily graphic because a lot of people do not want to see a graphic you know surgery images or anything like that but you know just an image of him and him saying this was my life, just laying in this bed hooked up to this machine waiting for someone like so and so to make the choice to donate or you know something like that, but I agree with you, but I don't think it's

necessarily feasible to document their entire ordeal and then condense it but I think that one image of you know-a good representation of-yeah

This was placed on contrast to other videos featuring recipients, such as the one featuring Chicago Bears player Charles Tillman's three-year-old daughter, who received a heart transplant as a baby:

Me: Do you think um, do you think uh-can one of these videos be upbeat and serious at the same time do you think? Can you talk about organ donation you know with sort of a positive upbeat feel and...

Michelle: mmmm...I guess like after, like their afterlife, like after they got it

Amanda: yeah

Michelle: can be more upbeat

Amanda: mmhmm, like if you combine that first one we watched with the- with the little girl playing,

Me: mmhmm

Amanda: Like if they showed her in the hospital um or something like that, start it somber

Me: mmhmm

Amanda: "and then end it with her using her heart, you know, having her play sports or something"

In *Tyler*, a 15-year-old cadaveric bone transplant recipient explains his post-surgical scar and his life of athleticism following his recovery from cancer. Again,

participants seemed to expect an illustration of Tyler's illness, as if needing confirmation that he was sick enough to justify his transplant. In the first excerpt below, Joaquin jokes about not getting to see the surgical scar Tyler describes in the video, then changes his tone to a serious comment on the video's content.

Joaquin: awww. How come he didn't show us the scar?

J.T.: h h h

Joaquin: Why only the ladies? [laughter]

Me: Well looked like it was kind of in a sensitive place, but, you know

Joaquin: No, it's you're right, but you know still, you know, you gotta...show it...Shoulda showed the scar, wha-what really happened.

In the next excerpt, Julie describes how adding more images of illness would have enhanced Tyler's story, just as it did for Steve.

Julie: I think that one had a much better impact than the two um other ones again because he was young um and it only showed one tiny little sad picture of him with a cap on but maybe he could've lost hair from radiation or whatever but I think it's important to not-and it doesn't have to be graphic but...proof-

Daniel: it's the details that really-

Julie: -it's the details and I think it makes a more emotional impact when you see someone who has suffered who is now able to walk around and live life and end happy I think that they did a good job of you know when he was eleven or whatever he hit a rough patch and it was bad and I hate to say it but kind of s- showing people who bad it is and you know [sucks teeth] I think it's necessary too



with donation and with kind of pushing that sense of urgency? because it is rather an urgent issue I feel to kind of highlight that people wait for years sometimes to find a donor or a match so I think that um proof I hate to say it but proof of suffering, more sad pictures of him in a hospital would have had a more emotional impact, yeah he's all happy and golfing teenager now which is great positive ending but maybe it didn't follow that progression of hey this is a bad time this is proof of it wasn't fun had to wait and blah blah blah and now we're happy and alive and yeah”=

Why do these participants prefer to see scars, oxygen tanks, and hospital beds? It is perhaps easy to discount as an innately human fascination with the grotesque (see also rubbernecked onlookers to highway accidents or box office receipts for horror films), but seems in this context to go deeper. There is an element of mistrust behind their words, as if pictures provide proof where words cannot, even in this age of Photoshop trickery. Just as no commercial hawking fad diets or exercise devices would be complete without before-and-after photos transforming the morbidly obese into the swimsuit model, there seems to be an expectation that a story of radical transformation from invalid transplant candidate to hale and hearty transplant recipient must also be confirmed pictorially. In the next chapter, I discuss the underpinnings of mistrust throughout these focus groups in greater detail. This is but one example of such skepticism toward the practice of donation.

Besides mistrust, however, there is also within these excerpts a tacit implication that a recipient must truly need an organ to be lifesaving, as though a recipient's need somehow justifies the death of the donor, and would there not be need, the donor need

not have passed away. The tyranny of the gift, it seems, is not merely a construct of guilt within a recipient's mind—it is a societal expectation. Recipients must be wholly deserving of their transplants.

In the next excerpt, Jamie makes visible her processing of Steve's video by admitting that she judges the recipient. She suggests that additional information about his condition would make it easier for her to judge him deserving or undeserving of his transplant.

Jamie: Like what he meant by that because um, what did he ha- he had fibromyalgia or?

Jeremy: Cystic fibrosis

Emily: Cystic fibrosis

Jamie: Cystic fibrosis. Uh, I mean like some people wouldn't even know what-

Emily: Cysti-yeah"

David: What is that?

Jamie: -what is cystic fibrosis, what happens to your lungs when you do that-

David: and then they had to go into that in that really long commercial

Jamie: -because I immediately thought with the lung thing I'm thinking, well are you a smoker, you know like h h h [David laughs] that kind of thing and um but then when he finally said it it still I mean it would be good to have like an explanation of all of those types of things.

While previous research has noted "the gift of life" as a frame, the content analysis described in Chapter Three found that the variable "gratitude" loaded strongly

onto the frame, resulting in “thank you for the gift of life” as a significant frame. The presence of that gratitude is intriguing, because it suggests a critical point from both a health communication and critical-interpretive standpoint. Gratitude is an important element to display when organ recipients are onscreen, but despite the language of altruism that permeates practically all donation discourse, it situates the organ as a commodity, albeit one that can be neither bought nor sold. As Joaquin notes in the next two excerpts, despite his veneration of Kerry throughout the video, Steve is not grateful enough and should be doing more good in the world to pay back his donation.

Joaquin: And didn't it show him hugging the family thanking the family you know or like came at the grave site of the person you know thanking the person like delivering flowers you know or thanking the family all the time

Me: mmhmm

Joaquin: Sending a card every year that she passed you know, thanking them for that

Joaquin: Well you know he should also be like going to like uh organizations like helping people, is he is he also involved with other stuff?

Me: mmhmm

J.T.: Yeah

Joaquin: You know like organ donating is he going and helping people you know and all this kinda stuff

Michelle: Like talking at their-

Joaquin: A-After he got it is he just oh forget it, I got it, you know, I'm better, hey I'm thankful but uh, I don't care about everybody else that h

J.T.: h h

Amanda: yeah

Me: Sure

Joaquin: He should be involved and stuff like that

Me: mmhmm

J.T.: Or you know at least let us know if he is

Focus group participants imply a recipient must be *worthy* of the organ he or she receives, and must display appropriate gratitude. Examining this on its face, it seems an almost absurd expectation. The donor died, most likely not intentionally, and most likely not ever having met the recipient, let alone choosing him as anatomical beneficiary. It is certainly not the same situation as that of a living donor, to whom gratitude may mean something. The description of an organ as a “gift” implies that it holds some intrinsic value as a commodity that would be ordinarily bought, sold, or bartered. Given the thriving black market trade worldwide, an organ most certainly does have an associated price tag. Its recipient must then be deserving of something so valuable.

Although a common and positive frame, using “thank you for the gift of life” to frame a message creates a number of hurdles to interpretation that, even at four minutes long, Steve’s story does not have sufficient time to address:

1. It turns registration and transplantation into a value proposition by commodifying the organ, which flies in the face of the intent of altruistic donation language.

2. By humanizing the recipient, he or she must be eminently likable. Although overall reactions to Steve were that he seems like a nice guy—a sort of everyman—it now frames the issue around whether *this guy* is deserving of the organ, and prompts evaluations around age, race, mannerisms, individual need, and so on, as Jamie reveals in the excerpt above.

3. The recipient cannot be simply grateful for the organ; he or she must be *sufficiently* grateful for the organ. Saying “thank you” is not enough. One must display gratitude in accordance with the value of the organ, and that—given that the organ represents life itself—is all but impossible.

For these reasons, I suggest the preponderance of messages framed strongly around “thank you for the gift of life” are not as effective as believed.

#### 4.4 RISKY CHOICES

The message that prompted this research in the first place was the Every 11 Minutes campaign produced by Donate Life South Carolina. My first prediction, upon seeing the video was how unpopular it was likely to be, lacking personal narrative, relying upon statistics, and framing the issue negatively (in terms of loss) rather than positively. If you do not donate, it seems to imply, someone will die.

Yet despite the negative framing, this video proved itself to be among the most popular across all groups. Following Kahneman and Tversky (2000) and Smith and Petty (1996), the negative framing will be more effective if donation is considered a risky choice and/or audiences engage in effortful processing. In the next excerpt, taken from a group of all non-donors, Sherman notes the impact of the ad.

Sherman: I liked it, it was quick to the point, it was catchy you know the names and the eleven, the number and then the moment of silence.

Tara: mmhmm tells you something you didn't know that every eleven minutes

Stacy: Yeah-

Tara: So that was catchy I mean it was informative. Short to the point. h h h

Stacy: Yeah I didn't know that

Sherman: It was quick

Stacy: I was kinda waiting for some more but h h h

Sherman: I liked it. Quick. That's a one o'clock in the morning [laughter] so

The most salient characteristic of the video, which participants from several groups brought up unprompted, is the sense of urgency. Many participants—even those who did not care for the video overall—found the sense of urgency created explicitly by the statistics about need and more subtly by the ticking clock and bright red palette to be an effective element. In the next excerpt, Jamie and David riff on this concept.

Jamie: Well then you even have the eleven seconds to think on your own about what it is that they're saying, you know, and this idea and the connection, and it-it is kind of-it is still a personal though, thing, cause you have the signatures and the names up there with the visual part, um

David: And I like that they disappear in the end, if you're watching it you're saying oh all those people are dying because I don't have an organ donation

Jamie: Right

David: On- checked on my driver's license.

Me: So it's-it's making you think about death then as you just brought up-

David: mmhmm. and the color's nice.

Me: h h and the color's nice,

David: Nice red and white, I don't know exactly why I like that but I like it for that video, better than black. black would be more depressing. Red symbolizes fresh organs h

Jamie: h h yeah I was thinking about that too h h h

Emily: Yeah h h

But perhaps it is not the *framing* of the video that prompted positive reactions overall from focus group participants. It may instead be the presentation—short and succinct, at 30 seconds and relying on slick graphics rather than talking heads. One cannot conclude that negative framing is more effective than positive framing without a direct comparison to a positively framed ad sharing similar production values.

The “Givers” ad created by the New England Organ Bank is also 30 seconds long. A mellifluous narrator speaks over images of Mother Teresa, firefighters, and uplifting images of communities and people banding together and joining hands. Throughout this montage, a computer-generated ribbon flits from photograph to photograph, providing a sense of unity and motion throughout the ad, literally tying the brief narrative together. Based on what framing and organ donation communication literature would suggest, this advertisement should be among the most popular. After all, it frames donation positively (giving) rather than negatively, as “Every 11 Minutes” had. It includes no overtones of death, need, or grief. Whereas participants would view Steve’s story and process whether

or not they believed him sufficiently deserving of an organ, the overarching theme of community would dissuade commodification of organs. The warm and fuzzies of “The Givers” provides the perfect counterpoint to the solemn urgency of “Every 11 Minutes.”

Participants, however, almost universally *disliked* this video, not for its production values, but for the message itself. It was muddled, confusing, and banal. Multiple groups commented on how the lack of direct mention of organ donation throughout the ad would lead one to assume the commercial has to do with charity groups rather than donation registration. In this excerpt, Sherman, Stacy, and Tara agree that the ad is nonsensical.

Sherman: I was confused with it.

Stacy: Yeah I was too

Sherman: Like it was a united way commercial h h h h

Tara: That was mother Teresa wasn't it?

Stacy: yeah, yeah it was more- it wasn't enough, it just showed people doing stuff but it didn't-

Sherman: Like they wanted money h h h

Tara: Wasn't real relatable you know.

Sherman: Give to the United Way.

A group of Lexington donors agreed, as Jamie attempts to soft-pedal her dislike of the video. When Emily agrees with her, she expands.

Jamie: I think it's gonna be really hard for me to say that I don't like any of these commercials because the message I think is- I-I mean I'm an organ donor so I



think it's important, but I-would say I'm not real fond of this one because I didn't-I mean unless-because I knew we were watching videos about organ donation, I'm not sure I would really know where they were going with this, with the whole givers thing-

Emily: Yeah, that's true

Jamie: Because they don't really see anything about organ donation until the very end and you could go with the beginning of that up until they say organ donation,- you could go with the vast number of different things, you could be like feeding the hungry or-

Emily: Charity in general,

Jamie: -any yeah any char- just general charity

Nevertheless, these two videos are not *perfect* counterpoints. “Every 11 Minutes” uses statistics to create its argument, while “The Givers” does not. “The Givers” does not even use personal narrative, such as “Steve’s Organ Donation Story” or “Tyler”. Its message is structured around platitudes. Could a short, well-produced, positively framed video using statistics instead of narrative prove more effective than “Every 11 Minutes”?

One video in the sample, “Mascots on a Mission” was part of a month-long campaign from Donate Life Illinois featuring videos of organ donor “mascots” as they go through a training camp to promote donation. The videos are intentionally absurd, no doubt mimicking popular ad campaigns of the time such as GEICO’s cavemen that rely on offbeat humor, recognizable characters, and repetition to raise salience for a product or issue. Similar to “Every 11 Minutes,” “Mascots” includes statistics citing the need for

transplantable organs, as the mascot's "trainer" yells at them in his best drill sergeant impersonation.

Humor is a risky choice when the topic at hand is, literally, a matter of life and death. Although some participants laughed, others found the video to be tacky and nonsensical, as perfectly summed up in this exchange in Sumter; I prompted the group's response after an awkward pause.

Dave: Ohhh man

Flora: It was weird h h

Dave: It was awkward

Flora: But you're like thinking about it weird, like that's just weird.

Robert: Where to stick this card if you ain't wearing no pants [laughter]

Shelly: Yeah like really?

Shelly: Well I'm kind of intimidated I felt like I was in basic training being told to do something again like

Dave: Not as bad as the grandma though h h h

Eileen: It was supposed to be- it was supposed to be donor mascots but they had an alligator and-

Alison: Yeah I didn't quite understand like-

Dave: Yeah what is that? h h h h [laughter]

Flora: That's what I mean like you're still thinking about it like what did I just watch?

Alison: Just trying to figure out what-what the mascots were, I would rather see like a heart or you know organs

Flora: I know was that a tooth at the end?

Dave: h h h yeah it was a tooth

Shelly: I think it was a kidney?

Flora: oh [laughter]

David: Oh it looked like a tooth, looked like a dentist tooth

In the following excerpt, participants note that organ donation does need to be handled with a certain degree of solemnity. It sat particularly poorly with one group of non-donors.

Me: So do you think that I mean you can't really- is it hard to talk about organ donation and I mean- I'm not saying this was funny, I will not go that far but um but do you think you need to have a little bit more-

Tara: Seriousness

Me: Yeah seriousness when you're talking about organ donation?

Tara: Yeah you do or-

Stacy: Yeah now how that boy did his how he kinda made light of the situation and kinda threw a little joke in there, that's ok

Tara: That's different

Stacy: But to make a whole joke about it like that, no. you can't expect anybody to take it seriously.

Tara: You're exactly right that's what it is just funny yeah

It seems then that it is not just a question of narrative versus statistical structure or facts versus platitudes. The negative framing of “Every 11 Minutes” was, overall, more effective than the positive framing of “The Givers” or “Mascots on a Mission”.

#### 4.5 FRAMING OF ISSUES

To test the framing of issues, I used a video in which an “expert” speaker typifies a claim about donation. In this example, a vice president of operations at an OPO addresses what she terms “myths and misconceptions” about organ donation and religion. I examine discourse around religion in more detail in the next chapter. Here I examine the effect that the speaker’s role as an expert plays in the effectiveness of the message frame.

Put simply, her role is problematic for many of the focus group because expertise itself is a subjective term. The setup of the video makes it clear that she is presenting in the role of expert; the video is titled “Ask the Experts”. But focus groups demonstrated that her expertise is called into question. Non-donors in particular found her to be unappealing and a poor spokesperson for discussing religion. In the excerpt below, Tara seems unconvinced by her assertions. Sherman suggests her role within the organization actually threatens the validity of the message.

Me: Um how about her a speaker as a spokesperson, did she work for you did she not work for you?

Stacy: She was alright.

Tara: Yeah she was okay but she wasn't- for me, she wasn't totally convincing because she didn't- it didn't sound like she had any facts so.

Me: Alright cause she was a member of the organization and not a member of the clergy?

Stacy: mmhmm

Tara: mmhmm

Sherman: She was the vice president of operations, trying to recruit [laughter] get those numbers. cause that's what I looked at, I was like oh vice president of operations, oh she's gonna promote it. I guess who the message you know what they preach, in health who's giving the message you know and I believe who they are. She wasn't convincing. At all.

Tara: No, not really. Like she really didn't know for sure, but just kinda talking.

Sherman: Excellent question.

Me: If that was the message she was trying to portray, what would be an example of maybe a better spokesperson? I mean not maybe somebody who's at least more charismatic that you know.

Tara: Well as far as the facts, if she were to come out and said um there were um statistics that say that uh such and such church-you know religions- religion agree to donation or not, you know just more statistical information versus cause it just kinda seemed like she was just talking to me, like she didn't really know, just like you said there weren't any real factual information.

Sherman: A minister probably would have been good, even a minister's wife saying you know they are organ donors or whatever, they donate some-somebody who's part of the church who had somebody to get a donation. someone- we gotta know somebody h h and that's what I was like, child you know anybody [laughter] how they doing? No! That's- I had somebody who had that they almost died. [laughter]

Donors were more split on the question of her expertise. In Lexington, Brandon is upset by the content of the video, calling it “complete bullshit.” When asked about her as a speaker in the next excerpt, Kate and Brandon recast her role as alleged expert as instead merely a paid shill.

Me: So how bout her as a speaker, message-her message aside-um you know being a member of this organization uh did she work for you as a speaker what are your thoughts about her as a speaker?

Brandon: I think she presented her inaccurate information well, she spoke clearly i-i-it's kind of the same thing as the last, it's a good speaker, I just don't agree with-

Sara: Like inaccurate information

Kate: She didn't seem very happy, like she was just telling you cause it was her job, that's what it felt like to me, not that she wanted to tell me, but that's who she works for and she was told do a commercial-

Brandon: Yeah. I was paid to tell you this. yeah.

Kate: Yeah. so. just felt kind of put on.

Sara: Maybe she didn't like her facts either. [laughter]

Brandon: That very well could be I've-I've seen that-I've seen that before where you'll have a speaker come on and be like this is what we're talking about, it's like you don't-you don't agree with that statement, do you? h h

On the other hand, Emily—also a donor from Lexington—finds her role and message to be refreshing. Emily notes repeatedly throughout her focus group that she dislikes emotional ads and finds them manipulative. This video, she notes, presents *facts*. David dislikes the video, but it's Jamie who attempts to (as is her fashion) very politely explain her problem with the speaker: she comes across as too dry and academic. Emily ends up agreeing, seemingly backing down from her original stance, and the conversation appears to stall. I prompt them with a question to continue the discussion.

Me: So in-do you think that message could have been delivered um, w-I-I guess a-a question to ask would be she's you know she's a representative of an organization that exists you know to coordinate transplantation of organs and the donation of organs, um, does that do you think that lends her authority, or do you- um does that make you- uh I guess- is she a good person to be giving this message about organ donation and myths or religion?

Jamie: I think that she's the right person to do it, whether or not she's capable of it is the question-

Emily: Yes. Yes.

Jamie: -you know because I mean you-you can't get a messa-if somebody's not-if someone gets turned off by the way that you say something, um then they-they're not-you're not going to get the message across as effectively as if it's somebody that's likable I guess you could say.

Emily: But you still have to have the authority of-

Jamie: Exactly.

Emily: You know of having-a-assuming she has the-the knowledge base to answer all these questions

David: But what if instead they had a religious leader on there? Would he be better necessarily than her as a-speaker?

Emily: ahhhh that's questionable because that's gets-that's gets-that's really specific.

Jamie: Well then that would be kind of- that would be like favoring one particular religion or whatever

David: Well you could do multiple speakers.

Emily: Yeah.

Jamie: Have like a panel of h h of clergymen? h h h

David: Exactly, and just have like you know where you do the person talking-

Jamie: Yes we agree.

David: And then it's one sentence but several different people say the part of it, and they're all different clergymen for different religions saying this is fine.

Emily: Oh. No.

In the course of that exchange, the speaker's role shifts from the academic expert to someone who has no authority whatsoever to speak on matters of religion and donation. This is a perfect illustration of how using an expert to typify claims is not an effective framing strategy for organ transplantation. While her expertise may not be called into question during videos asking technical questions about donation (for



example, what organs can be donated), these are not “claims” to which the issues framing model would apply.

This is because that, perhaps unlike other health behaviors, organ donation is so inextricably tied to meaning and culture that one cannot be universally perceived as an expert. When it comes to religion and organ donation, David suggests showing clergy on screen as authorities, but what of the Southern Baptist preachers that do *not* support donation? Is their expertise no less valid?

Beyond religion, almost every aspect of donation is fraught with controversy, with claimed experts on both sides of the divide. Consider Arthur Matas, transplant surgeon, arguing in support of a regulated market for live donation (1977:25) while Nancy Scheper-Hughes, an anthropologist having served on a United Nations commission to examine the black market organ trade, militantly opposed (2004)? Medical experts do not agree on the criteria for declaration of brain death (Truog and Robinson 2003; Kim, Fisher, and Elliott 2006). Who is correct?

Framing organ donation as an issue by using “experts” as communicators will be unsuccessful, because none can unquestionably claim expertise about meaning. Using those with personal experience with donation, such as Steve, Tyler, or even Charles Tillman, is a more effective strategy. Such communicators speak from a highly individualized point of view and do not claim expertise—only experience. Although there were themes of mistrust which will be discussed in the next chapter, no focus group participant questioned these speakers’ authority to speak about donation. Claiming ownership of knowledge about the meaning of donation, however, will not encourage donation registration. It will lead only to more questions.

#### 4.6 REPRESENTATIONS OF GENDER

It goes without saying that an advertisement's effectiveness is not determined solely by the cluster of elements constituting its frame. The communicators themselves play no small role in the interpretation of messages (Scheufele 1999). Here I explore how the characteristics of the communicator, or speaker, in the videos played for audience shaped the way that they interpreted the messages and illustrated cultural beliefs shaping cognition.

As found in the content analysis described in Chapter 3, gender as a speaker characteristic was split fairly evenly among males and females. Although both anthropology and public health as fields of study have rightly embraced a non-dichotomous view of gender, no videos reviewed for this study discussed sexuality or gender in any context, nor was my focus of the content analysis one that examined representations of gender (e.g. proportion of women appearing as physicians versus organ recipients) in any but the most superficial way. If any transgendered or other gendered speakers appeared on screen, I am unaware; I coded their gender according to the most obvious identifiers. This is not to discount the value of a future study examining organ donation in the context of gender and sexuality—especially considering ongoing controversies concerning the prohibition against men who have sex with men as blood or organ donors (Ison et al. 2011).

I did not find gender to be a salient characteristic affecting the framing of messages. For most participants, gender did not rise above the level of subconscious processing unless prompted. In one group from Lexington County, however, gender did emerge as a theme, prompting a debate about the effectiveness of male and female

spokespeople for organ donation. In the following excerpt, I asked the group about the male narrator of the New England Organ Bank's "The Givers" advertisement. Participant Jamie is discussing her preference for a female narrator. David then appears to be egging on his wife, Emily, who already said she despised the ad for its attempt at what she terms "manipulation."

Me: I had-I had somebody who was adver-as it turns out, I hadn't met them before, but they had studied advertising in college and they were in one of these focus groups, so it's great to kind of have different mindsets, but we were just talking about the-the gender you know um and you-you said you thought it would be more effective as a female?

Jamie: I think so yeah I think with the giving and the caring and the emotional part of it because you know women's speech tends to be more emotional whereas men's speech tends to be more commanding, I don't want to say authoritative because that's sexist but, you know just more to the point you know women go around and around a lot of times, not that that's a bad thing,

David: They're not succinct.

Jamie: -cause it's not, but I'm just saying, I think it would've-I think that probably would have been a little bit more effective, not that the message-I don't think that the message part being lost would have been that would have answered that issue, but with the ribbon and the caring,

David: I don't think the-I don't think it suffered, I don't think that the commercial suffered with the male speaker, but it might have gone in more- you get more enhancement out of a female speaker than you would that male.

Emily: It would've- No, no, it just would've annoyed the crap out of me even more,

David: Well we already know that you hate commercials that involve emotion”

Emily: “Yes, I-I-I-I pretty much really disliked this commercial anyway, so you- I mean doing- you know adding another layer of attempted manipulation would have just made me want to gouge out the producer's eyes.

These examples do suggest that gender may be an important aspect of framing with a very real impact on audience response. They do not, however, suggest a definitive, universal preference for one gender versus another, or how the perception of that speaker changes based on the interplay of gender and role. Such a determination could be made only with a detailed, targeted study in which other frame elements and speaker characteristics are controlled to tease out the specific impact of gender on audience reaction to organ donation messaging.

#### 4.7 REPRESENTATIONS OF RACE

As with gender, race *in the context of speaker characteristics* was noted but rarely discussed explicitly. In the next chapter, I discuss in detail how race and ethnicity as elements of culture drive discourse about organ donation. As this chapter is focused solely on those salient themes emerging from participants discussing elements of the videos themselves, rather than the videos in the larger context of organ donation, I present here only evidence in which the race of speakers was discussed.

In the following excerpt, David (who is White) brings up the race of Charles Tillman, the football player whose daughter received a heart transplant, suggesting that

his appearance may have been an attempt to appeal to minority groups. Jamie politely disagrees, thinking that he was chosen for his celebrity status, his race being inconsequential.

David: Ummmm, it's interesting that he was- that they chose a Black actor. well, celebrity.

Me: How so?

David: Mm, you know you could have a- there's plenty of people to choose from, there's plenty of celebrity people in the Ohio area that you could choose from, so it's interesting that they decide to gear it towards that ethnicity.

Jeremy: Why do you think they did that?

David: Um, it's hard to say if they're in Chicago area I'd assume it's because there's a great proportion of African Americans in the Chicago area, if it's a rural area, you know they're doing it more for, you know name recognition possibly and people know his name better than they know other peop- you know other people but you know the problem is because it's not-targeted for here, it's hard to really know their motives.

Emily: What team did he say he played for?

Jeremy: Uh, Chicago Bears

Jamie: Chicago Bears, okay, so I guess really I would say is- is that I don't know if they were targeting a particular, um ethnicity with that rather than like trying to go after someone who's really well known because of his um occupation you know because and football is such a you know American thing you know that he

would be someone that people would trust because you know it's such a beloved American sport and that kinda thing, um.

Later in that focus group, David again brings up race, as his wife Emily discusses the blandness of the spokespeople in the context of age.

Jamie: Yeah, but it would have been better if there was an older person and then a younger person to have that contrast between the two different age groups and also the genders, you know because there was a male and a female in this one,

David: Both of them white

Jamie: Both of them white, yes, yes

Emily: Very white, their hair was white, [laughter], that was the whole thing was white! h h h h

Jamie: Well and they again too that-that brings in a very good question, well the only commercial that we've seen so far though i-with color has been the first one,

Emily: with someone of-mmhmm

Jamie: hmm.

Emily: Yeah, I think that's what kind of- those two were just like, I don't know, just really I mean they were very homogenous

Note that in both of these excerpts, the participants do not phrase their observations of race in terms of personal preference, instead stating—in vague terms—how *others* might prefer an ad based on the race of those appearing in it. In contrast, in a Sumter group with a very diverse group of participants—identifying as African-American

and Pacific Islander—Michelle discusses the eponymous star of “Steve’s Organ Donation Story” in the following excerpt, in which I ask her if the video is effective.

Michelle: I think it depends one on what channel you're showing it on, two, two the difference between the two videos was, he actually said that for three years he had false alarms, whereas oppose for Charles Tillman they didn't say if they had false alarms or whatnot so it just depends on the-the little messages that are in there that may like differentiate that aspect and how it's gonna touch but I would more relate to this person because I liked that he looked as if he's from a minority group, you know like, race or whatever, so it just like I guess that appealed to me ish

The other Sumter group had a similar response, appreciating the diversity they felt Steve represented.

Flora: For me h h h Uh yes for me it was a little bit more effective because um, I come from an island so um the chances are of hearing of organ donors for people from a small group as opposed to coming from like being in the states and predominantly seeing you know Caucasians or African Americans show-it just shows that that help went you know, down the line so it's like, because I don't really ever hear of like organ donors helping and we're part of the U.S. h h h so it's just kinda like

Me: For you? mmhmm.

Eileen: You guys have to fly to like, come back to Hawaii

Flora: It's just funny, like we have to come all the way out here and like the help is very scarce and limited, so it's just nice to see that even though he did probably live in the U.S. for his whole life that it's just a different people of people that is being shown.

Again, as with gender, the specific impacts of race as a speaker characteristic are difficult to glean based solely upon these focus groups without a controlled study. These results do suggest that audiences comprised of underrepresented groups prefer messages in which onscreen participants are likewise of an underrepresented group, which corroborates other research into race and organ donation (Callender and Washington 1997; Jacob Arriola, Perryman, and Doldren 2005). Nevertheless, it is a generalization that cannot, given the limited evidence of this study, be used to inform future campaigns, save for a reinforcement of the importance of audience segmentation, including by race and ethnicity.

#### 4.8 REPRESENTATIONS OF AGE

Age did appear to be a salient characteristic in participants' reactions to videos and was frequently discussed throughout the focus groups. Three videos presented three very different age groups: "Charles Tillman" showed images of the speaker's three-year-old daughter, saved by a heart transplant. "Tyler" presented a narrative of a fifteen-year-old boy receiving a bone transplant to preserve his mobility after an earlier bout of bone cancer as a child. "Hank and Dana" featured two elderly organ recipients briefly sharing their experiences with donation.



Multiple participants identified children as a surefire way to elicit their sympathy, suggesting it was a highly effective characteristic for the promotion of organ donation, as in the example below when Eileen talks about Charles Tillman's daughter—a three-year-old girl receiving a heart transplant:

Me: Great so um, so do you think you mentioned uh seeing the little girl in the video and um,

Eileen: Right yeah, if it were just him it probably wouldn't have the same effect h  
h

Me: Right so you think it's one of the things that makes it effective is seeing that, that recipient, especially a little girl um, do you think it would be as effective if his daughter were, say, twenty?

Eileen: No. I don't think so. Just cause we were like, well, I don't know. I think just her being younger cause you want—I mean you always want her to have a chance at that young age to go through something when they're that young, so I don't know how you would do it if they were older.

Of course, following the adage of “You can't please all of the people all of the time,” Emily noted her distaste for advertisements featuring children, finding them to be manipulative. Here, she discusses “Organ Donor Myths: Religion,” which played following the discussion of “Charles Tillman.”

Emily: I liked that style of video way better.

Me: How so?

Emily: Um, it feels more like they're just trying to get information out, that they're just trying to clarify misconceptions, you know I-I don't feel like somebody is using small children to push a message on me, um, that sort of thing.

“Hank and Dana” prompted discussions of the efficacy of advertisements featuring older recipients. Many participants, however delicately they tried to phrase their responses, shared the attitude that seniors are not effective spokespeople for organ donation. Bluntly put, the organs would be wasted on them. In the following excerpt, Joaquin describes his discomfort with the idea that an organ would be given to an elderly person rather than a younger one.

Me: So you think that showing the, the um, you know, older adults is not as effective maybe?

Amanda: As they use children, yeah

Joaquin: Yeah

Michelle: Yeah, if they used, I mean if they used like an adult and they both already, you know

Joaquin: And what about like a, you know an eighty year old that needs a heart and a three year old after you know is behind him on the list, would that eighty year old give it up for that three year old, you know, that kid? I mean,

Me: Right

Amanda: Like, the really technical stuff

Joaquin: Are they gonna give it up for somebody else to live where they already lived, you know

Me: Mmhmm

Joaquin: It should be like an age kinda thing where you know,

Amanda: mmhmm

Joaquin: The kid should be first or you know,

Me: Sure

Amanda: Yeah

Joaquin: Than a eighty year old and a three year old, it's like, man,

Me: Right

Joaquin: You took my heart, h h, you know, you don't know how long you're gonna live after

J.T.: h h h

Joaquin: Kid, let the kid live couple years, you know

Michelle: Experience the

Amanda: Yeah

In the next excerpt, I asked one of the groups of donors from Lexington about the speakers' age. Kate and Brandon responded quite candidly.

Kate: You don't put two old people in a commercial for organ donation when especially one of them was a high school football player that he got his heart from like dude you're gonna die in ten years it's-like-you have to have balance somewhere in there

Brandon: Yeah I will say it does-like the-I can't remember which commercial I guess video number four cause it's the only one I have a check mark on um, the-

the fact that the one in video number four, the guy who got both of the lungs from the girl where he was I think he said he was up there in his forties, I think he said early forties when he got lungs, like that, you know that might have taken a guy who his life might have been cut off in five to ten years with the cystic fibrosis whereas he gets two new lungs, that might have just doubled his lifespan, I mean instead of dying at fifty, he might have lived on to eighty or ninety or something like that, like that's awesome, that's-that's great but when you're taken people who are one-like Hank-Hank looked like one foot in the grave and another one on a banana peel [laughter] like he was ready to go anyway and-

Sara: How many old people do you see? he was not that old h h h [laughter]

Brandon: My-my mind distorts things, I'm sorry

Kate: Well, yeah, I agree

David, as he did throughout the focus group in which he participated, disagreed with the others in the room, finding a comforting familiarity in the visages of Hank and Dana:

Me: Right, and I kinda want to ask something David that you brought up, which is that you-you reacted more positively to it, the idea that you know I mean he mentions the young man saved my life, um, so you reacted more positively to organ donation, um seeing that it's going to old people-or older adults versus younger people?

David: Well, I didn't like this commercial because it was confusing and hard to understand, and my complaint is they didn't have young people, BUT saying that,

and this sort of emphasizing that organ donation is for old people in my experience, that's not a bad thing, because my grandparents might need organs, so that would give me a reason, because I'm thinking oh they get a replacement organ, I get longer with them, so it brings it to a more personal level than someone-than necessarily than someone telling their life story and how great it is for them and now they can see their kids, all I see is oh it's an old person that's like my grandparents. I want my grandparents to be around longer. They might need an organ.

Perhaps the most fascinating aspect of the discussions surrounding age in these videos is that focus group participants were so forthcoming in not only bringing up the speakers' ages, but discussing them in the context of deserving or not deserving of transplantable organs. It suggests both a generally held bias favoring youth over age, but that expressions of such biases are not as socially stigmatized as expressions of race or gender bias. It is certainly plausible that focus group participants viewed each White female or African-American male speaker and made decisions, consciously or subconsciously as to whether that speaker was deserving or ill deserving of an organ transplant. Yet no participant expressed those biases in the course of the focus groups, understandable given both social stigmas surrounding explicit racism or gender discrimination and the diverse makeup of many of the groups.

Even in the context of a controlled study, in which all other framing characteristics could be controlled save for the demographic appearance of the onscreen speaker, it is unlikely that an overt connection could be made between race, gender, and

audience response, though correlations may indeed emerge. Given those limitations, these cultural constructs must be explored critically in a larger context of discourse surrounding organ donation. In the next chapter, themes of race underpinning these groups are explored in depth in a critical-interpretive context.

#### 4.9 DISCUSSION

It was not fruitful nor the purpose of this study to rank videos by preference. The purpose was to elicit conversations about the videos and test whether assumptions about the effectiveness of frames held true in a context of organ donation and transplantation. That said, the video most generally liked by participants varying by gender, race, ethnicity, religion, and donor registration status was “Every 11 Minutes”—the campaign that I learned from DLSC was not based on existing evidence or research. I also found that positive message frames were not necessarily more effective than negatively framed messages. Although to a certain extent, I sought to find whether the “Every 11 Minutes” ad, and indeed the whole campaign, were predicated upon a faulty and dangerous message as literature would have one believe, I instead found that it was among the most effective frames tested. I will not state outright that much of the scholarship of framing theory is wrong based on the results of these focus groups. I will note that these findings do perhaps lend some challenging food for thought for some traditionally held conclusions about framing, but may, however, speak more to the difficulty of effectively framing organ donation.

Although certain positively framed messages, such as “Steve’s Organ Donation Story” were well received, they introduced challenges. Featuring an organ recipient elicits a judgement decision about whether or not that recipient deserved the organ he or

she received, making the communicator himself more salient than the message frame. Do the elderly deserve organs, when a child could potentially need one? Were Steve or Tyler genuinely so sick that they needed transplants, and if so, where is the proof? Organs, couched in rhetoric of gifts, become commodities—perhaps not to be bought and sold, but with a very real value weighed against a recipient’s need. A recipient must show suitable, sincere, public gratitude to the giver or be judged harshly. This demonstrates a kind of dual subjection of the physical body. Foucault writes,

“This political investment of the body is bound up, in accordance with complex reciprocal relations, with its economic use; it is largely a force of production that the body is invested with relations of power and domination; but, on the other hand, its constitution as labor power is possible only if it is caught up in a system of subjection...the body becomes a useful force only if it is both a productive body and a subjected body” (Foucault 1977:25)

In the context of organ donation, Foucault’s statement rings true as well; the body is useful and productive posthumously, and laws regarding organ donation crafted to maximize the productivity of those bodies—especially within countries following the opt-out model of donation registration. Focus group participants reveal an expectation that even after death, the donor body is of course “useful” and—as will be discussed—among some donors there is some sense of societal ownership of these organs that supersedes the right to bodily integrity of the donor. While both donor and non-donor participants indicated a sense of bodily autonomy that would refute such a concept, some states and other nations have experimented with opt-out systems for organ donation. That is, the organs belong to society after death unless one makes explicit his or her wishes.

Tellingly, the groups revealed that rights of bodily autonomy apply only to the donor, as will be discussed in more detail in the following chapter, leading the second subjection of the body to be that of the recipient. Focus group discourse revealed thoughts about the dichotomy of illness and need versus total recovery, coupled with a requirement of gratitude. The organ, despite the illegality of its sale, nevertheless has very real value. It is both a commodity and an instrument of the “political technology of the body” as Foucault describes, in that knowledge of it “...is not exactly the science of its functioning, and a mastery of its forces than is more than the ability to conquer them” (1977:26). The recipient’s body, now functioning with a donor organ, is subjected to a new level of societal scrutiny—the need to *prove* both one’s need and one’s worth. Discourse surrounding the images of Steve, Tyler, and other recipients is markedly different from that of any other class of person. We do not question any human’s right to breathe, but we do question Steve’s right to breathe with, as he puts it himself, Kerry’s lungs.

Perhaps donation is considered a risky choice, because the negative framing of “Every 11 Minutes” was effective overall among focus group participants. Or perhaps it is more simply that focus group participants were engaged in effortful processing, as described by Smith and Petty (1996). Certainly, being asked to sit and discuss organ donation advertisements for 90 minutes meets the criteria. Would this ad, viewed in the wild, still be as effective versus an ad such as “The Givers?”

Ultimately, as the case with Steve, the role of the communicator is the overriding factor in processing message frames. All processing is typically done on a subconscious level, and being asked to reflect directly on the effectiveness of advertisements and



individual communicators is a difficult prospect for focus group participants. During the course of these groups, I attempted to make visible the schemata participants use to process messages that, under ordinary circumstances, they may not give a second thought. While focus group participants were more willing to discuss less controversial aspects of speakers—such as their roles, or their ages—they were more hesitant to discuss race. It is inevitable that every participant, upon seeing an image of a man or woman in these videos, made a value judgement on the worthiness, trustworthiness, and likeability of the person onscreen. But these judgements are made in a much broader context of structure and meaning and may indeed lay completely beneath conscious processing. As Goffman (1986) suggests, frames are constructed of more than the elements dissected in the excerpts above; they are constructed within a cultural context. While participants rarely discussed these cultural constructs guiding their cognition explicitly, it does not mean that they do not impact the processing of frames. It also does not mean that these cultural contexts cannot be learned through these focus groups.

In the next chapter, I attempt to tease out these cultural constructs and political and economic structures that guide interpretation, meaning, and effectiveness of these message frames.

## CHAPTER 5

### DISCOURSES ABOUT ORGAN TRANSPLANTATION

#### 5.1 SCHOLARLY DISCOURSES ABOUT ORGAN DONATION

The corpus of biomedical literature has focused on developing quantifiable models donation behavior, just as it has with other health behaviors. As discussed in the first chapter, authors suggest that by understanding the broad categories of determinants that underpin willingness to donate, campaigns can design more effective messages or interventions. Testing the myriad hypotheses and models of health behavior that underpin the body of literature on organ donation behavior is well beyond the scope and capacity of the present study or its methods. Exploring common themes of the biomedical literature through ethnographic focus groups can nevertheless provide critical insight into the models and biases of scholarly discourses around donation behavior. In this chapter, I test these commonly held beliefs *about* commonly held beliefs against the themes that emerged from seven semi-structured focus groups held in different communities, among a diverse group of participants, across South Carolina. I will demonstrate that certain reductionist models of donation behavior are not only ignorant to the complex layers of culture, knowledge, and experience that underpin decisions *not* to donate one's organs, but have contributed to a societal discourse around donation that has unwittingly stymied efforts to increase donation rates.

## 5.2 THE ROLE OF RELIGION

In the nascent stages of this project, I attended a public event to promote organ donation in South Carolina after invitation from a contact at a group connected with an OPO<sup>7</sup>. After the event, I was introduced to an individual who worked with one of the organizations sponsoring the day's activities. "Brian" asked me about my interest in the subject; after all, I had no direct connection to donation—I was not a recipient, donor, or family to either.

"Well, I'm interested in how communication—specifically advertisements—affect donation registration. I wonder whether some commercials work better than others at promoting donation, and whether some might actually turn people off of the concept."

"You want to know why people don't donate in South Carolina?" he asked. "It's because of all these Southern Baptist preachers spreading ridiculous lies that people won't go to heaven if they donate their organs. They're the problem."

I understand Brian's frustration. As one working with those promoting donation and believing so thoroughly in the nobility of the act, he saw donation promotion efforts undermined by leaders of the very communities whose messages of sacrifice, love, and kindness were synonymous with his own. Brian felt betrayed. Religion should be an enabler of donation. Instead, it was a barrier.

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<sup>7</sup> Although my reasons for attending the event and the purpose of my project were fully explained to those with whom I interacted during the event, these interactions took place prior to obtaining IRB approval to conduct ethnographic interviews and focus groups. Consequently, I have scrubbed these interactions of all identifying information, but I believe their message to be too pertinent to omit from this section.

Although I sympathize with Brian, and although I do not *personally* agree with the notion that bodily integrity is a prerequisite for a peaceful afterlife, I wholeheartedly disagree with the application of the principles underlying his sentiment. These are:

1. Religious rationalism: There is a knowable, universal religious truth (at least when it comes to organ donation)
2. Humanism: The lay health promoter is a better source of scriptural interpretation than an ordained minister (at least when it comes to organ donation)
3. Ingenuousness: Non-donors are unable to think critically when presented information by a religious authority

I will leave to the theologians the debate over scriptural interpretation and will instead use this section to discuss not the merits of his argument, but its effects as a message when realized in video form. Brian's *beliefs* about the role of religion in donation behavior, while founded in some kernel of accuracy, have clouded a deeper understanding of reluctance to donate among the population. It is the promotion of the dismissive cynicism about religion—not religion itself—that may be responsible for a low donation rate.

In the OPO-produced video titled “Organ Donor Myths - Religion,” an introductory text scroll reads:

*Millions of Americans allow common myths and misconceptions to keep them from registering as lifesaving organ & tissue donors...We asked some Illinois residents to share their donation questions...And an organ donation expert to shed some light. Get the facts!* (Organ Donor Myths - Religion 2009)

This text raised eyebrows of some non-donor participants. In a group of non-donors from Richland County, Stacy immediately questions the information in the video. As discussed in the previous chapter, the speaker's credentials as "expert" are already under scrutiny. Here, she and Sherman expand on religion's impact on that incredulity.

Stacy: Now is that just like her opinion or was that like facts that she found out?

Me: That's a good question

Stacy: Cause see you know things get a little touchy when you throw religion in there.

Me: So i-if you don't mind expanding a little bit on that, when you say things get touchy

Stacy: Well you know like when people um state their opinions about- that's what I was wondering was what like- was that like facts that she knew or was it just like that was her saying that believes or thinks that uh religious people-certain religions don't like- was that factual or was that just her saying

Sherman: that she heard from somebody or

Me: I don't know

Stacy: Cause if it was just like her opinion,

Sherman: Mmhmm and reading the sign said get the facts and then it showed religion and some- maybe some folks had said she had went to some churches how they go and do these presentations, and the church said we're on board, we want to give life and promote it cause they get the facts was the reason and you know just hearing it so that's what I thought

Stacy: The FACTS

Although the expert—a vice president of operations at the OPO—ends the video with a relatively benign suggestion to “check in with your clergy, check in with the people who may have answers for you, but don’t assume without that information that donation is not a possibility,” her earlier statement that “in reality, every organized religion is in support of donation” irked some participants—including donors—who recognized that the billions of people worldwide who are *not* Christian or Jewish were dismissed offhand. In the following, Kate and Brandon (who are Christian) take umbrage on behalf of others.

Kate: Yes, that one alienates half of the world because it didn't even address their religion as organized religion

Brandon: Yeeah, the other thing is I'm fairly certain that what she said is complete bullshit [laughter] I could be wrong about that but h h h h

Kate: Yeah

Brandon: I mean you have things like the Jehovah witnesses where I would consider that an organized religion I don't agree with the viewpoints but I would consider it an organized religion and they are very much anti transfusion anti uh-

Kate: Anti medical care, yeah

Brandon: Pretty much anti medical care, and it's one of those things where-are you saying that's not an organized religion or are you saying that they don't understand their own belief system or? I don't know it-it-I feel like she really left out massive portions h h of the world population in that-I mean even American population in that single statement there so

Focus group participants watched a second video featuring religion prominently: a celebration of a national “Donor Sabbath” that displayed passages from scripture followed by images and quotes from deceased donors. The video has a two-part message: the first states that donation is a holy act (a religious twist on the “gift of life” frame), and the second is a remembrance of deceased donors. Interestingly, donors in focus groups found this video to be among their least favorites, as in the excerpt below where David suggests the video is harmful to the donation message.

David: Would have already agreed to it it-it-it's not going to convince anyone and it'-it-and that just makes it a non- non-effective PSA cause I mean it's one of those things where if you're not convincing it-cause PSAs in- in their...existence are made to persuade you to a certain way of thinking and that one absolutely would fail at it I would just about say about a hundred percent of the time

Jamie: Either that or they're-yeah-

Emily: -it's not going to convince anyone-

Emily: Well that or if you do it's gonna be so tied into like oh I did it because I was convinced that if I was a real Christian I would do it-

David: And I hate that kind of stuff yeah

Emily: but that's-I think it-it's tying in a lot of baggage that you don't need to tie into organ donation.

Non-donors, on the other hand, appeared to be much more positive about the inclusion of scripture, as in the Richland group below, where Tara and Stacy (both

African-American non-donors identifying as Christian) note that they liked the video's message.

Tara: The Bible verses were nice yeah but just too much reading you need to- if you want to convince me-you gotta do some talking

Stacy: Like I liked the concept like showing you know who gave what and you know the bible verses and I liked that part, I liked the concept of it but it was just way too fast and way long.

Me: So um did you agree with the message I mean obviously it had a religious message to it with the scripture and everything in there did you agree with that?

Stacy: Yeah it was kinda saying if um if God could you know do all this stuff for us why couldn't you do all that for someone else kinda so I liked it. It made me think twice.

In the next excerpt, Stacy, Tara, and Sherman explain a cultural taboo against donation. Sherman has a unique perspective as a funeral director:

Stacy: That's a lot of- not a lot of- what do you call it? Um like not religion but what do you call it like tradition kind of? You know like how you grew up here that kind of thing

Tara: Just don't give your org- don't donate your organs yeah

Sherman: mmhmm old traditions mmhmm

Sherman: And you know a lot of older folks years ago they didn't believe in like the autopsies and stuff and on to they said you have to start doing them it's the law that certain stuff, we just don't believe in you know cutting-



Tara: cutting with the body

Sherman: -when they you said just bury them in peace, and all that- and we haven't had a lot of you know organ donors as we see, we see a lot of African Americans the folks who are going around educating and stuff you know you don't see a lot of the faces that look like the faces of the story- we don't look at getting the kidneys as an organ donor process we just say so and so need a kidney, I'm just hiding all the process behind getting the kidney

Perhaps, religious practice does not create non-donors; cultural constructs shape attitudes about donation, just as they shape religion itself. In the following sections, I will examine these constructs and attitudes and posit a model for donation behavior which incorporates religion not as a primary factor in donation behavior, but as an interrelated force of culture which shapes and is shaped by political-economy.

### 5.3 BODILY INTEGRITY

Focus groups did reveal other cultural differences among participants and between donors and non-donors. Non-donors (and donors discussing non-donors) commonly brought up themes of bodily autonomy. In the excerpt below, Nelson describes a scenario from his personal experience in which his grandmother did not consent to the donation of his grandfather's organs. There is a subtext that, even after death, her husband's organs were not hers to give:

Nelson: I know the uh the biggest thing whenever my uh my grandfather passed they asked uh my grandmother if uh she was okay with uh you know giving his organs, and uh the biggest thing was that she wasn't-she wasn't comfortable, she

didn't-she didn't feel like it was-she didn't-it wasn't that it wasn't the right thing to do, she just didn't feel like it was an oka-it just made her feel very uncomfortable, she ended up not you know saying no, she didn't want to and uh so I-I think you kn- the-the biggest thing is just like uh the uncomfortability. so.

Shelly: Especially cause it was-it wasn't-like she probably felt like who am I to say if he wants, you know what I mean, like

In another group in Sumter County, Joaquin—a non-donor—suggests that he would prefer to depart the earth corporeally intact, although he originally couches his reluctance in terms of the quality of his organs.

Joaquin: Oh well I'm not taking care of my own body myself you know, h h so why would I you know, I'm living my life too, doing whatever I want to do, you know

Me: Sure

Joaquin: And you know I-I came in the world with it, I'll just die with them, you know

Other non-donors also brought up this notion of leaving the body intact. In a Richland County group discussing the “Organ Donor Myths-Religion” video, Tara notes that she is not sure where the idea that religions are against donation came from. Stacy and Sherman suggest the notion of bodily integrity, tying it back to a religious statement they have heard before.

Tara: um I don't know cause it's hard to tell cause we don't know-I mean you don't- unless you do some type of survey or something you wouldn't know how churches feel about it, but like I said I just never would have thought there would have been an issue with that in the churches because you're-

Sherman: -if the churches say do it.

Tara: -because you're promoting life instead of trying to you know take it away or what have you or end it. I don't know.

Stacy: Well is that because you're supposed to keep what you have to yourself or something?

Tara: I don't know

Tara: Oh like keep your own- like if you die, keep your own heart

Sherman: Yeah-and-and my only thing that I'll-mmhmm you need to leave it with everything you come with

Tara: So that your temple and all, cherish your temple. hmm, interesting.

Stacy: Because your body is supposed to be a temple?

The “body is a temple” quote mentioned in both non-donor groups comes from 1 Corinthians, “Do you not know that your bodies are temples of the Holy Spirit, who is in you, whom you have received from God? You are not your own; you were bought at a price. Therefore honor God with your bodies.” (1 Cor. 6:19 New International Version). Although the use of this line implies a link between donation behavior and religion, participants did not indicate that this narrow interpretation of the passage as applied to organ donation had any real bearing on their donation decisions.

Although the excerpts from non-donors indicate a sense of bodily autonomy that may influence their decisions to not donate, this is not fundamentally different from donors' perceptions of the body; neither group indicated a belief in societal ownership of one's organs. In the excerpt below, Michelle makes notes of this.

Michelle: -yeah and it's a choice too. It's like- it's like- it's not something that's gonna like be detrimental to your life if you don't you know like if you don't give your heart you're gonna die you know [laughter] so it's like- it's like a forceful type thing ins- and not really trying to help you but trying to help others which is okay but instead of like you know the cigarette commercials they're scaring me to try to help you like stop smoking or you're gonna die but I think if- I think it might be a little too much cause you should give somebody a choice to want to do that instead of like trying to bully them into giving up a lung or something, that's just wrong I think

In the next excerpt, I follow up with one donor participant about her reaction to the “Hank and Dana” video, which ends with Dana looking into the camera and very forcefully telling viewers to register as organ donors, with a brisk “Do it now.”

Me: So, do you, you, you mentioned Sophie that you found the bossiness there to be

Sophie: Yeah, I don't like that

Me: You don't like that?

Michelle: No

Joaquin: No

Sophie: It's your choice, you know,

Joaquin: Yeah

Amanda: Mmhmm

Sophie: And it's something that belongs to you, because

The conclusion that non-donors are “selfish” (Cleveland 1975) cannot be drawn from these focus groups; if selflessness is the idea that one's organs belong inherently to others, then no participant proved himself anything but selfish. The difference of bodily perception between the two groups lay in the understanding of the body *after* death.

Non-donors discussed the body after death as though it still maintained some fundamental link to its owner in life—hence the discussion of the body as temple—whereas donors discussed the body after death as though the loss of human consciousness yields only lifeless parts. In the next two excerpts from two different Sumter County groups, donors discuss this notion of lifeless parts.

Flora: It doesn't seem reasonable to want to take your organs with you, if you're dead, you're done with them, somebody else could use it, I mean it just seems silly not to. So

Nelson: They can take whatever they want after I'm dead

Dave: yeah

Alison: h h h

Nelson: I'm not gonna use it

In the next excerpt, Stacy and Tara—non-donors—discuss the sentiment that “you won't need them when you're gone,” demonstrating that even non-donors exposed on

one hand to the “cherish your temple” concept of bodily integrity also feel a sense that one’s organs are not necessarily needed after death.

Stacy: How you're-when you're gone you're not using it anyway so you might as well you know-

Tara: -help someone else

Stacy: -help someone else. so they can live.

Me: Do you agree with that?

Stacy: Yeah, I do. I do. In a sense.

The story does not end here, however. Although donors discussed their *own* bodies in terms of the physical rather than symbolic, they too mentioned a donor’s organs “living on” in another. Here, Lexington donor Brandon begins discussing the “myth” that recipients take on characteristics of their donors when his wife Sara jumps in with a story in which her family experiences that phenomenon. Brandon makes a face of disbelief, prompting his wife to chastise him and explain.

Brandon: The whole thing-the whole thing though there's you know the interesting myth behind organ don-I-I don't believe it at all anyway but the whole thing you take on certain parts of the people's personalities who are donating the organs to you and so that's kind of where that idea that kinda story comes from, but I never-

Sara: Well my-my dad has told me this that my-not that

Brandon: I know, I know

Sara: Stop rollin your eyes [laughter] um my mom's stepdad actually had a heart transplant, I mean he was-he was pretty old when he got one and I forget what food it was but there was something that like he never had in his whole life ever wanted and then he started just like craving all the time and I-I wanna say that's-I think he was-I can't remember if he was told that the person liked it, I don't know, I've heard that a lot of times that you know, I never used to like this food, now I do

In Sumter County, Alison makes the point about “living on” after death when she reacts to Steve’s organ donation story.

Alison: She could have been a normal person but because she donated now she’s kinda still living because her you know her lungs are in another person

While this may assuage the grief of donors’ families, many participants expressed discomfort at the “Frankenstein syndrome” (Sharp 1995)—even referring to its namesake, as in the excerpt from Sumter below.

Dave: I think just individually like if it was Kerry’s family they probably feel a different way about it, like my dad donated his eyes to- to the donation and if somebody came back and said like, I’m seeing with your dad’s eyes, I’d be like, whoa...alright. That’s nice. That’s cool h h

Alison: That whole phrase is creepy

Dave: [laughter] Exactly! don’t keep saying that, but h h h

Eileen: It just makes me think of like those horror movies when they do like I mean I'm this sounds probably like it's gonna be horrible [laughter] but you know what I mean it makes me think of like those-

Shelly: -Frankenstein

Eileen: Yeah like where they become the other person because they have their heart or you know like it just makes me think of that for some reason I don't know.

Sara and Brandon, donors from Lexington County, described the uncomfortable nature of donation most succinctly when discussing an OPO-produced video:

Sara: yeah, well I mean if-if you think about it it's a pretty brutal concept-

Brandon: It IS a brutal concept

Sara: And so when you reduce it so that you know try to fit both of these people into the commercial it ends up coming across as a brutal concept.

Brandon: Brutal concept, yeah

The notion of the “brutal concept” is an intriguing one. Despite the prevalence of positive framing of donation as a beautiful gift, it is still a bitter pill to swallow. Neither donors nor non-donors can easily situate the technology, its successes, or its failures within a worldview that seems almost universal among participants: that the body is more than simply a sum of its parts. The thought of partitioning embodied flesh that still retains some aspect of its original owner yields discomfiting and dissonant attitudes about donation.



## 5.4 THE ROLE OF EXPERIENCE

As I have stated elsewhere, I am an ardent supporter of organ donation and, having weighed the ethical considerations carefully throughout the course of my work, my opinion of the practice as fundamentally good has remained unchanged. Nevertheless, my early studies of donation led me to question my own preconceived notions of the motivations behind donation registration. In an unpublished 2010 study examining evidence of cognitive dissonance among focus group participants discussing organ donation (VanderKnyff and Ranta 2011), I encountered the narratives of three very different non-donors. One, an African-American female undoubtedly pressured by her participation in a large group of donors, indicated she had just forgotten to renew her donor status. A second, a White female confidently discussing her non-donor status admitted her status was a result of a fear of death—not selfishness or superstition: “I’m scared and worried. I’m the person... I’m an only child, and I’m a little bit of a control freak, so I don’t really like things that I don’t know and are out of my control. It concerns me and I’m worried.”

The story of the third non-donor, a White male, most intrigued me. Once an organ donor, a personal tragedy led him to reevaluate his donor status:

“It’s kind of scary. I was in an accident. It was a bad accident. I was in a coma for about three months. Got 340 stitches on my face, went through the windshield. They thought something went into my stomach, they weren’t sure what was going to happen. But I’m all me right now. I don’t know, it’s just a little bit scary. Going through it, I guess... You never think about it happening to you. My view is maybe just a little bit skewed...I broke my neck, my back, I was messed up. And

when I was alive, I got this car...When I was able to open my eyes and see again, I think, wow I wished I had kind of died. It hurt so bad.”

His mother, he claimed, argued to keep him on life support when his doctors recommended pulling the plug. In short, his life was saved by the reluctance of his family to offer him up as an organ donor. The experience stuck with him and, as I listened to his narrative, it stuck with me too. Compared with the innumerable quips from donors (myself included) explaining that their decisions to donate were made thoughtlessly—a split-second inability to answer the question “why not?”—here was a young man whose life and future had hinged upon the decision to donate his organs. Although his decision was arrived at after self-reflection and personal experience, it does not necessarily elevate it as more valid than a quick decision to register. It instead revealed to me that when communicating with non-donors, operating under the assumptions that their decisions were arrived at by lack of knowledge or awareness and that asking them to think *more* about the decision may not yield an immediate change in behavior. Rather, operating under an assumption that non-donors may have knowledge of and experience with donation and have thought carefully about their decisions not to register will allow OPOs new avenues to acknowledge sources of hesitation without condescension and better target communication.

With this in mind, I paid careful attention to the narratives that non-donor participants in the present study offered as shaping their decisions and found again a careful thoughtfulness. Sherman led a double career as a health promoter and as a funeral director, encouraging life and facing death. Having prepared bodies of donors in the past,

he witnessed firsthand the physical consequences of organ procurement on the corpse and has seen the startling effect on the family when donor status was unknown.

Sherman: I just- and my part when I hate- like when I say what about- like my thing I don't like I won't say don't like- I'm uncomfortable when we get a body at the funeral home, being a funeral director, and they been an organ donor it takes so much more for uh for the embalmer to prep and you have to get forms signed by the family again in case the- it don't go right or they don't look like themselves, I just say you know a lot of people-

Tara: Oh from the removing mmhmm

Sherman:-do the organ donor, that's just my thought about that

Me: Like for an open casket funeral and it makes it more difficult, or?

Sherman: It's a lot harder for the embalmer to you know to embalm them so they can be viewable when they've been an organ donor, I mean the eyes and everything is all gone so you gotta rebuild you know to make them look normal so and they bust and then it's extra work like if you're the director seeing the family you gotta say now you all know they were an organ donor, sometimes the people didn't even know but and so that's why, I think the highway department says you know share and tell the people, and then you know you have to show them the drivers license if they were on the driver- why they did it or they're wanting to say well when- why don't y'all- why we can't have the funeral this day, you're saying well the organ you know the people still got the body still taking the organs or whatever.

Perhaps more disturbing was Sherman's anecdote on the safety of transplantable organs:

Sherman: Mmhmm the ho- well well what we heard was like we told the family that you know why that body was still at the hospital, they're waiting to take the tissues and the eyes and stuff and they just started screaming and hollering and saying like you know we don't want that to happen and all this stuff and then one of the other family members said well I'm sure she didn't tell them that she was HIV positive!

During that group, Stacy told of an encounter with the wife of a kidney recipient, who had told her about her husband's less than successful transplant experience.

Stacy: cause um I was out of town and I met this lady she just happened to be sitting by me and her husband was with her and got sick and-and had to leave and she was saying that she just leaned over and said oh I just feel so bad for him cause she said that he needed a kidney transplant that's when you have to have dialysis right? He needed a kidney transplant, well she said his transplant didn't take and she said that they had been waiting waiting waiting you know when they get all these calls and these false alarms so she said that um Duke I think she said it was called, she said she was from Columbia too she just- that's how you know she started talking to me she said they called at three a.m. in the morning they said get in the car, you know get here as soon as you can- maybe it was Charleston but I thought she said Duke. But anyway we got um we got a kidney. So they did that. They jumped in the car, and she said they didn't grab anything, they just took out,

and when they got there they did the surgery and everything and the first night he was ok but then he started rejecting the kidney? Oh well I take that back. ok before when they got the call it was their counselor or whatever and she said we've got a forty something year old kidney a forty something year old female kidney for you blah blah blah blah, ok and then she said after they did the transplant and they started- the transplant started rejecting, um another counselor came in and said ok, well you've got the kidney of a 71 year old such and such and such and it was much older than what they were told and so she was really upset about it but they tried to brush it under the rug with saying no you must have misunderstood, and she was like no I know I didn't misunderstood- misunderstand you know I guess I don't know if they would have thought twice about getting a 71 year old but it was really upset and she said he was rejecting it and now he was back and having dialysis again and he was a little winded and wasn't feeling real good and he went back up to his room, cause we were in a hotel yeah, went back up to his room and um you know just take a break for a minute, and I guess he does- maybe does dialysis you know how you can do it on your own for all those hours? But it was just- I know that's not donation but h h that's not transplant but it was the- you know the age thing. That was probably a factor in him rejecting the kidney.

Me: Did it affect your view of organ donation at all, to hear that story?

Stacy: No, it didn't. I didn't even think anything about it, you know connecting the two.

Stacy: Well, in a way I guess it does because I'm con-I'm concerned with the age thing. So when you think about it like that h h um, I don't know

Stacy: There's gotta be an age limit

These narratives reveal the influence that personal experience can have on an individual's attitude toward donation. The power that a positive experience with donation can have on shaping attitudes is easily seen; the plethora of OPO-promoted videos on YouTube in which healthy recipients or their family members discuss donation stand testament to this phenomenon. Less documented is the way that a negative experience, equally personal, changes perceptions. These narratives contribute to moral panics over organ donation and transplantation.

## 5.6 ORGAN DONATION AND MORAL PANICS

The story, as I first heard it, was that of a young man traveling to Eastern Europe. At a bar, he meets a beautiful woman, and the two strike up a conversation. They order another round of drinks. Hours later, the man wakes up, groggy from the drug covertly slipped into his drink, in a bathtub full of ice and a sharp pain in his back. Scrawled in bright lipstick in the mirror above the sink is a brief, terrifying message: "I took your kidneys."

It is a frightening tale, although one rife with logical inconsistencies (why leave the man alive at all after signing his death sentence?). Nevertheless, it has captured imaginations and become a fixture in popular culture references, although more recently told with a nudge and a wink. The location changes; the victim travels to Latin America or the Middle East or even Paris. The story is, of course, an urban legend. To date, no such tale of woe has been reported or confirmed anywhere in the globe (snopes.com

2008). Yet how does such a story gain such traction—not just in the United States—but elsewhere?

Urban legends are retold and spread not as ghost stories, but as cautionary tales. “Oh, you’re going to Prague this summer? Watch out for your kidneys, dude” carries more cachet than, say, “You’re climbing Mount Everest this summer? Watch out for yetis, dude” precisely because—no matter how improbable—there is an element of believability to these stories stemming from xenophobia. Whether it is an organ-snatching succubus or an adopted dog that turns out to be a gigantic, Mexican sewer rat, urban legends play on our tendency to mistrust the Other. Former Communist republics are, of *course*, highly corrupt. And who knows what the Mexican government dumps in its sewers? You already know you can’t drink the water.

These stories are not simply folklore: they are artifacts of moral panics. Writes Cohen (2011):

“Societies appear to be subject, every now and then, to periods of moral panic. A condition, episode, person or group of persons emerges to become defined as a threat to societal values and interests; its nature is presented in a stylized and stereotypical fashion by the mass media; the moral barricades are manned by editors, bishops, politicians and other right-thinking people; socially accredited experts pronounce their diagnoses and solutions; ways of coping are evolved or (more often) resorted to; the condition then disappears, submerges or deteriorates and becomes more visible.”

Englund notes, “Mass hysteria or psychosis is not at issue, because the subjects of a moral panic are able to analyze the causes of their distress and are adamant about the

values they seek to defend” (2006:172). Though the fear may be overwrought and the flames fanned by untruths, moral panics are, at their core, founded in a kernel of a culturally perceived truth. Campion-Vincent (1997) groups theft rumors into three categories: kidnapped babies and children sold for parts, *Sacaojos* or “eye thieves” kidnapping and stealing children, and kidney theft. In Latin America and Eastern Europe, these first two narrative types almost always involved wealthy foreigners kidnapping the victims (although in Guatemala one rumor circulated that the kidnappers dressed as clowns to lure victims—thereby fueling the Stephen King-esque archetype of the demonic clown). Campion-Vincent argues that these first two categories of narratives developed out of mistrust of predominantly American neoliberal policies and interference in the economic and political systems of democratically elected governments across Latin America. The third category, that of kidney theft, she traces to a tradition of the “White slavery” narrative: that of the exaggerated but not wholly untrue accounts of human trafficking and enforced prostitution dating back to the 19th century<sup>8</sup>.

Based on my findings from focus group participants, I would argue that there are two more narratives that can be labeled, broadly, as “organ theft” narratives: that medical

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<sup>8</sup> Campion-Vincent traces the “bathtub of ice” narrative to 1990 Germany and its original incarnation as a couple traveling to Istanbul, feeding on German xenophobia of Turkish immigrants responsible for the postwar reconstruction of their nation. Although I agree with her finding, I suggest that this story’s rise to prominence in the U.S. during the early 1990s closely matches growing concern over the increase in use of “date rape” drugs in bars and other public places. While the threat of rape may be sufficient warning to young women to watch their drinks, the comparatively low incidence of rape of men would not lead to the same concern. If the end result of a drugging were not an evening in the company of a beautiful woman, but rather the loss of one’s vital organs, men may be equally hypervigilant when drinking in public. Other than timing, I lack evidence to support this contention, but I recognize my own bias: I first heard the “bathtub of ice” story from my mother in middle school, a nurse practitioner and not a particularly superstitious person, followed directly by warnings about date rape drugs and the need to be exceedingly careful in accepting drinks—even sodas—from people I don’t know.



practitioners will kill a person (whether by action or neglect) to harvest his or her organs for transplantation, and that organs harvested (even legitimately) from donors will be transplanted into wealthy recipients. By linking these narratives with the categories of stories discussed by Campion-Vincent, I do not mean to suggest that they are mere urban legends or should be taken no more seriously than roving gangs of homicidal circus performers. I instead wish to demonstrate that stories of biomedical injustice and inequality are spread using the same mechanisms and rooted in the same cultural patterns as these other narratives. And unlike killer clowns, these stories may actually be demonstrably true.

Taken as a whole, these five categories of narratives reveal two starkly different worldviews: the subaltern's fear of wealthy White people, and wealthy White people's fear of everyone else. Neither I (nor Campion-Vincent) note any version of the narrative in which the bathtub full of ice is located at an Embassy Suites next to an organic grocery store. Instead, the story always plays on fears of the Other—a traveler to a foreign land (even to another wealthy, predominantly White country like France) seduced and deceived by a local *femme fatale* or, as Campion-Vincent notes, a Western tourist in need of medical care in a developing nation whose kidney is removed during surgery. Note, however, that all other categories of narrative occur close to home: it is the Guatemalan baby snatched from his bassinet or the Mexican child nabbed off the street on her way home from school. It is the American doctor in an American hospital allowing an (African-) American patient to die while putting in a call to a sickly billionaire to alert him a heart has just come available.

Non-donors frequently brought up themes of mistrust and inequality, prompted by the “Taxi” video produced by Donate Life America’s partner Yes Utah! that sought to dispel the “myth” that doctors will let one die to harvest his or her organs. Instead, the reverse happened; it reminded participants—non-donor and donor alike—that such an incident could happen. Tara admits she shares that concern. Sherman makes light of it, but Tara continues and brings up *Have and Have Nots*, a fictional TV soap opera the group later discusses, in which doctors attempt to remove a man from life support just to harvest his organs.

Tara: It was weird he gets in the cab starts talking about that? BUT makes a valid point because that is my fear.

Me: You've heard that before?

Sherman: If they know you're an organ donor, they'll let you die.

Tara: I have-No I mean that is my fear is that um like if you're on life support they'll be more quick to take you off than let you- I want you to let me stay on as long as I can h I don't care if all-I don't care, let me stay on there because you never know-

Sherman: -You're never gonna want to hang around. Take her off! [laughter] Take her off!

Tara: -what God has in store for me, I could just wake up-

Tara: -little have and have nots. I mean it really has been a concern of mine, you know they'll- they'll say oh he's an organ donor ok ma'am I think you need to- family needs to go ahead and decide h h h to take him off but I mean I know- I can't say they would.

The group continues its discussion about the “Taxi” video, tying medical mistrust directly to race.

Sherman: They were just throwing that out about doctors you know because that's one of those myths we hear or you know we hear it.

Tara: I've often wondered about that.

Me: So-so I mean Tara makes a great point, you guys heard that before, the whole if you're on- if you're an organ donor they'll let you die?

Sherman: I've heard folks that have said oh don't sign up for the organ donors, something happens to you they'll let you die.

Tara: Let you die! h h h

Sherman: They know that they're going to let you die

Tara: I have heard that

Tara: You know that not- not a lot of African American minority people donate um

Sherman: Mmhmm well it tickled me

Sherman: We don't do that h h h

Tara: Y'all no seriously I have heard people say that

Stacy: I've heard that

Stacy: I've heard that part that they'll let you die

Sherman: You know the awareness in the African American community you know education awareness about it is one that we don't do and then we just don't trust folk when we know stuff like that saying child they'll kill you to go ahead

and get your parts [laughter] I'm not le- You know I'm leaving with everything I got h h.

Joaquin, another non-donor, notes that his mistrust of the medical establishment extends beyond organ donation. Amanda, a donor, quietly agrees.

Joaquin: I'm not gonna go to the hospital I mean yeah I need something but, I go there they just-you know, I don't need it, I'd rather stinkin live h h

Joaquin: They touch me I might die, you know

Amanda: h yeah

Registered donors, too, had heard the “doctors let you die” narrative before. Despite being an organ donor, Shelly admits having heard a variation of the story, in which medical technicians choose not to provide care in order to allow the organ donor to die.

Me: um so you mentioned that misconception um you know that doctors will let you die if you're an organ donor

Shelly: Or the paramedics

Me: mmhmm has anybody heard that misconcep-well, what they call a misconception um you know before? anybody heard that?

Shelly: I always heard that like if you're in a car acc-like a car scene whatever like the paramedics will let you die if you if you're an organ donor, not so much the doctors but the-the ambulance and the paramedics that respond and stuff are less likely to save a life if you're an organ donor h h h

Although most donors indicated that they did not believe the story, some showed hesitation to fully discount it. In the excerpt below, Alison notes the ultimate believability of the narrative, which convinces the rest of the group (all donors) to admit their concern as well.

Alison: you know that one person, yeah?

Flora: I don't want to believe

Flora: It could be, I DON'T want to believe it, but-

Shelly: I know right, like it's really hard to believe that way

Flora: But it's just one of those things that, stuck in the back of your mind like, are they gonna let me die? h h h

Alison: Always have that person

Me: Is it stuck at the back of your mind now?

Dave: [laughter] it is in mine.

Shelly: I know, I was like, I was like I wondered why they picked doctors, like I don't see doctors at all doing that like I said, they just, doctors being sued but,

The production values of the video itself, with its awkward script, acting, and premise (a pro-donation cab driver teaching her fares about donation), when coupled with the message tended to enhance the believability of a narrative that may otherwise have gone unremembered. David notes this strange connection in the excerpt below.

David: But I was thinking is the whole commercial you know especially at the end is you know oh doctors won't let you die, but she's off duty, she's going to murder you for your organs, she's an organ harvester!

Emily: Neither of them were doctors, sooo-

Jamie: mmhmm, yeah h h h

David: Don't have to be a doctor to harvest

Emily: So how the hell did they know what doctors are doing anyway? h h h

Jamie: Yeah, I think that-mm, yeah

David: There's a big disconnect between taxi driver and random person and doctors letting people die for their organs.

Alison: Yeah, that was a weird topic to-to pick for that.

Jamie: Yeah you get into a cab and you just start talking to your cab driver about like, I'm afraid they might let me die! you know h h h h [laughter]

Emily: Yeah that was just a super weird commercial.

Emily: Doctors don't let you die!

In another Lexington group, Kate, Brandon, and Sara make the same point.

Kate: Well and it-it had like the labels on the outside confused me too, was like- was that taxi just for organ donation purposes? h h h h cause it had-

Kate: This is the organ donor taxi.

Brandon: Yeah that's-

Sara: We'll take you to a special hotel [laughter]

Kate: That's-that's what it said

Sara: I got a room just for you

Kate: It had stickers on the outside that were like this is the organ taxi and that's-  
disturbing on so many different levels

In Sumter, Amanda and Michelle lightheartedly note that, though previously unaware of the narrative, the video actually prompted a new fear.

Amanda: It gave me a different perspective

Michelle: Doctors will SAVE you

Amanda: Right? I never thought that doctors would let you die, but now I think  
doctors might let you die if you're an organ donor h h h

Although no participant admitted that that popular culture references shaped his or her view of organ donation, many participants described movies or TV shows with themes of negligent or malevolent healthcare providers. Following an excerpt above, Tara discusses the role a TV show played in reinforcing her concerns about donation, as it plays into the narrative that the Taxi ad sought to contradict.

Tara: There was a show on now called the have and the have nots, a tyler perry  
show, I don't- h I'm sure you haven't seen that h h h

Me: No I have- I've seen- a commercial

Tara: Commercials? well this lady's son was hit by a car and he's on life support  
and at this hospital they said he was just dead, well his father that he just found  
out recently was his father that has never been in his life came to the hospital  
while the mother was- he was on life support and she was not- she was not taking

him off because she was a Christia- you know a strong Christian woman and she cried and prayed-

Sherman: God come and get him when they're ready

Tara: -every day and here comes the dad telling her- and he told her- she was like what are you doing here you never you know had anything to do with him before, and he was like you- you can't let that boy stay on child- I mean stay on life support you gotta let him go, you gotta let him go, and he said I've already talked to a doctor cause the dad needs a liver transplant and they don't know if the son is a match or anything but it is his son so he took her to court in this last episode and the judge ruled in favor of the father but I don't know if the judge knew that he wanted it so he could get a liver, but the judge ruled in favor of the father to have the right to say that he wanted them to go ahead and pull the plug on the son but his whole hidden agenda- wasn't even hidden really was for him to be able to get his body part! and it's that- you know it just goes to show and you know the mama kicked and screamed and all that, in a regular real court I don't know if that would have happened that way,

Me: Okay so this is like a fictional?

Tara: Yeah

Sherman: Oh no, not if he just reappeared!

Tara: Exactly cause the mother was the one that raised him and had everything to do with him and here this man comes with his lawyer and they said that the jud- I mean the judge ruled in favor of him but he's not gonna get it anyway cause the ma- the lady that the mama works for had him sent to a better hospital h h h and



they think he's missing but it just goes to show it's the same- you know the same type of thing, he was in the hospital I guess he didn't have any insurance and the doctor was trying to push her to take him off too, probably cause they wanted that bed but she would not let him go and then here comes this dad.

Sherman: They get ugly about that timeframe.

After the group recalled a few more examples, I asked them about the role popular culture played in shaping their views about donation.

Me: Did those affect you like seeing the movies with organ donation or whatever do those affect how you think about organ donation?

Stacy: Ythey scared the crap out of me!

Tara: Yeah kind of, it kind of scares you into not wanting to h h h

Stacy: h h scared the crap out of me, like oh my gosh

Tara: Wanting to have it done if something goes wrong

Husband and wife David and Emily argue about that narrative's plausibility. David says it happens in real life, but not on TV, so I ask him about a show he had mentioned earlier: *Grey's Anatomy*, which had also been studied extensively by Susan Morgan (Morgan et al. 2007) in examining mass media portrayals of donation.

Emily: Doctors don't let you die!

David: Well I can believe it happening in real life, but in TV it never happens, so.

Me: Not even in Grey's Anatomy?

David: They-they really really strongly contemplate it, but only because the guy's saying kill me, so that my organ can go to the kid, but they never actually say well we can just let you die.

Emily: David...

Emily: That's a really-that's a really gross episode anyway, I don't like it.

David: But it never happens! It's always like I'm standing behind my patient, we can't-even though we like their organs and this other person needs it, we're not going to kill them.

These videos elicited a common theme among donors and non-donors alike: a keen awareness of the inequality that characterizes the American medical system. The difference between the two groups is that the donors belong to groups that have, historically, benefited from such inequality. In the next excerpt, Brandon brings this up in the context of “Tyler,” in which the teenager talks about being able to play golf because of a bone and tissue transplant he received as a child.

Brandon: I think an interesting thing that is, that was brought up was the thing about him being wealthy, you know being golf and everything, but organ donation is not cheap, you don't see poor people with organ donation because of the cost of you know the medications just to keep the organ, it's-it's people who have money

Kate: mmhmm

Sara: I think if this kid had been a lower income kid they would have-they wouldn't have had the option to get a transplant and he would not have a leg.

Brandon: Exactly. So you know do you-theoretically yes, you want to spread the misconception that anyone can get an organ donation and thus everyone should be an organ donor, but realistically it's not that cut and dry.

In Sumter, Joaquin, a non-donor, brings up the inequality of the American medical system, suggesting that only the wealthy have a real shot at receiving organ transplants. This conversation follows the viewing of Charles Tillman's PSA, and Joaquin notes the inherent class difference between a professional athlete's daughter and others in need of transplants.

Joaquin: You might not stay alive long enough, because you can't afford the medication,

Me: Right, I mean you-you would need health insurance you know to be able to cover some of that stuff, um, so you can't buy an organ technically speaking but-

Joaquin: [Unless you go to Mexico] [laughter]

Joaquin: And then like-I mean if you-the list could take you three years and if you can't afford the medication to keep you alive for three years,

Michelle: Hospital visits

Joaquin: The hospital visits

Michelle: Operations

Joaquin: The operations

Michelle: yeah

Joaquin: And then what if you get a rejection? You're back on the list but you just spent all that money.

Amanda: Well doesn't that depend on what country you live in though, I mean because some countries do have socialized medicine, so

Michelle: If you lived in Canada, that wouldn't necessarily be an issue

Joaquin: The waiting list would be five years long

Eileen: Well unless you're super rich and decided to come to the United States and get what you needed then.

Dave: True

Dave: Well, he's a football star

[laughter]

Dave: I mean, he should have the money right away, you know, I mean, you know, you're on the list, but... You pay, you know, money talks some places, you know.

J.T.: hhhh

Me: You mean to get, to get the organ?

Joaquin: Yeah, you know. Sometimes whoever you are, you get bumped up on the list.

Joaquin: We have to feel sorry for him because he's a star and

Amanda: Yeah

Joaquin: You know, we need him, we need him

Amanda: You know, the top of the, they're the top of the totem pole, where we're the, you know.

Sophie: So he's not like, an ordinary person.

Later in the conversation, I prompt the group to continue. Joaquin again uses the phrase “money talks” to describe how organs are allocated.

Me: Um h-have any of you heard about the organ transplant list, have you heard that it’s fair or um that it’s not fair like who gets it-

Joaquin: You just gotta have money that’s all, it’s just money

J.T.: I think, it depends on what hospital you go to, you know, what practice is there

Amanda: Yeah

Joaquin: Money talks

Amanda: It’s a long long long list waiting list

J.T.: Yeah, I don’t think it’s a fair- like one hundred percent

Amanda: mmhmm

## 5.7 DISCUSSION

Regardless of the individual variables or theories used, donation behavior literature can be crudely clustered into a series of schools of thought. One school focuses exclusively on the individual donor or non-donor; one’s donation status is determined by constructs such as individual knowledge, attitudes, beliefs, religion, self-efficacy, and personality characteristics. In this school of thought, external factors such as cultural norms are, if acknowledged, viewed as having a moderating effect on the individual. Another school has explored behavioral decisions among donors and non-donors through a lens of racial and cultural differences, paying close attention to the role of the medical community and society in shaping perceptions of donation. The present study squarely

refutes the findings of the reductionist models of the first school, turning the models on their head; beliefs that shape donation behavior are rooted in *extrinsic* factors, such as real and perceived structural inequalities, and moderated through individual difference and experience.

Behind the “brutal concept” lies an ugly truth about organ donation: it is an objectively barbaric act. As Foucault (1977) notes, the spectacle of punishment has largely disappeared from the public eye; the cruel disembowelment and dismemberment he details no longer considered appropriate (or legal) punishment for crimes. Yet the very scene of 18<sup>th</sup> century torture and execution that Foucault describes is, arguably, the very process by which organs are harvested from “deceased” donors. The donor, kept “alive” by some medical definitions, is subjected to the brutality of the surgeon’s knife. While American society has largely sanitized the messiness of a gory death from the public consciousness—preferring instead to witness bloodless execution and content with euphemisms and digitally obscured video on the evening news—there is nevertheless a perhaps suppressed fascination with a violent death that is made conscious through discourse about organ donation. The brutality Sara notes reflects the ease with which an organ donation message can miss its mark in framing, and strike instead upon a chord that reminds the audience of death.

As found in the content analysis of donation videos and reflective of Sharp’s findings, OPOs create competing frames for the promotion of organ donation in a perhaps muddled effort to reduce these chilling thoughts. To potential donors, the organ is a lifeless piece of flesh that will not be needed after death but serves as panacea to those waiting. To families of donors, the organ is an embodiment of the donor through which

their loved one finds immortality on Earth. It appears to be organ recipients themselves who blur the line. Although most videos of the sample shown to the focus groups make no mention of donors or discuss them in general terms (e.g. “they donated, so I can live”), one video stands out in its treatment of the donor: “Circle of Life: Steve’s Organ Donation Story” features a recipient from Chicago describing how his life with cystic fibrosis improved after receiving a double lung transplant. The story of his improvement is unremarkable in the population of OPO videos, but his heartfelt narrative quite specifically humanizes his donor, Kerry, to the point that Steve notes, “I breathe with Kerry’s lungs.”

This was a popular video overall with focus groups, but the humanity that Steve imbues his transplanted organs triggered discourses that revealed that donors also do not separate the symbolism of the body and its parts after death. Given the responses of these focus groups, I find it difficult to criticize the beliefs of non-donors as superstitious or ill-informed when their perceptions of the body are not fundamentally different than those of donors; neither group cleanly fits the mold of Cartesian duality. How, in the same breath, can scholars, OPOs, and the medical establishment shame non-donors for their beliefs while continuing to produce and promote messages that frame donated organs as symbolic instances of the donor?

Furthermore, OPO efforts to combat perceptions of medical abuses and inequalities are tone-deaf at best and perhaps even harmful to their intended purpose. The narratives of wealthy Western baby-snatchers, malevolent healthcare professionals (or those using healthcare professionals as instruments of their own nefarious master plans), and international kidney thieves succeed in capturing imaginations and propagating

throughout societies because they play on culturally-held beliefs or frames. But the idea that a doctor or other healthcare professional will murder a patient for his or her organs is unique in that it is not simply reflective of cultural fears grounded in events or attitudes divorced from organ donation—it is instead, to some extent, *true*.

I do not mean that your average car accident victim that ends up in the emergency room will never leave, but that there are incidents on record that implicate healthcare professionals in what could be described as some form of organ theft. Scheper-Hughes (2000) discusses cases in which doctors procured organs from (presumed) brain death patients without prior consent. Although ultimately acquitted, surgeon Hootan Roozrokh captured media attention when he was put on trial for allegedly dosing an emergency room patient with a lethal drug to obtain his organs for transplant (McKinley 2008). Even if there has never been a confirmed case of an American healthcare professional killing a patient for organs, the so-called “myth” persists—and persuades—because it fits so neatly into a sordid pattern of abuse of the less fortunate to serve the needs of the wealthy.

Consider South Carolina: the grounds of the capitol building are guarded by the stoic glare of J. Marion Sims, founder of the science of gynecology, whose contributions to the Hippocratic arts were made possible by the controversial participation of slaves (Ojanuga 1993; Wall 2006). The infamous Tuskegee syphilis study remains a testament to the willingness of healthcare professionals to sacrifice the poor to serve the perceived “greater good” of society (Gamble 1997). The story of Henrietta Lacks’ unwilling genetic contribution to science was the subject of Rebecca’s Skloot’s (2011) bestselling account. Is it then so hard to understand how non-donors—in the focus groups of this study,



represented exclusively by people of color—could consider the same medical system guilty of such flagrant abuse in the past as similarly misguided when it comes to organ donation?

Although the U.S. system for the distribution of transplantable organs is among the most fair in the world, it is nevertheless still a rigged game. Apple founder Steve Jobs' well-publicized liver transplant in 2009 raised eyebrows; after all, he had not waited long on the list, and his pancreatic cancer alone would have made him all but ineligible for a transplant. Jobs received his liver by registering at multiple transplant centers across the United States. Because such centers will only serve residents of the area, he bought residences near these centers as well. When the call came for a liver, he was able to arrive at the center within the required timeframe using a private jet (Saletan 2011). None of what he did was illegal, nor can one fault a dying man for exercising self-preservation. Nevertheless, it was a winning strategy available only to the wealthy: most insurance policies (assuming a transplant candidate has insurance at all) will reimburse the costly genetic testing required for listing at only a single transplant center, so the cost at listing at multiple centers must be covered out of pocket. Buying a residence in multiple states is an impossibility for most, and the private jet is certainly out of the question. Steve Jobs did not “buy” a new liver, but the difference may be semantic; he spent a presumably exorbitant amount of money to procure an organ, regardless of the specific mechanism through which he received it. While his case is exceptional, it is still emblematic of a healthcare system that favors the rich.

Though ostensibly focused on advertising, these focus groups nevertheless illuminated themes of embodiment permeating discourse about organ donation and

transplantation. Participants discussed the physical body and social body amid seemingly contradictory meanings about organs as both soulless and yet imbued with meaning. Discussions of the body politic centered on bodily autonomy set against a backdrop of an unjust medical system. Nowhere are these themes represented fully in models of organ donation behavior.

In a critical review of psychological determinants of donation behavior, Radecki and Jaccard define “knowledge beliefs” as those “that can be verified against an external standard and, hence, described in terms of accuracy” (1997:185). The authors use “misperceptions and fears” as examples of knowledge beliefs; because the argument that “persons are maintained on life support unnecessarily long for the convenient removal of organs” is, according to the authors, categorically untrue, such ideas are demonstrative of a lack of knowledge and, consequently, a demotivator to donate one’s organs or those of a loved one. I would argue that the term “knowledge beliefs” is itself an epistemological oxymoron, but the authors’ point is thus: non-donors demonstrate less knowledge of factual<sup>9</sup> information and hold beliefs—labeled variously through literature and donation advertising as “misperceptions” (Radecki and Jaccard 1997), “myths” (Callender and Miles 2001; Feeley and Servoss 2005), or “misconceptions” (Organ Donor Myths - Religion 2009). Therefore, according to these authors’ theoretical models two aspects of this hypothesis can be tested: non-donors will demonstrate less factual knowledge than donors, and an increase in knowledge will lead to an increase in donation behavior. This

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<sup>9</sup> I choose this word carefully; although I wholeheartedly disagree with the authors’ use of perceptions of organ donation as true or untrue (as discussed later in this chapter), I consider “factual” to refer to those aspects of the donation process that can be verified—how and when to donate, legal intent versus consent, what organs can be donated, and so on.

is a simplistic application of theory that has been criticized before, both specific to organ donation (Yuen et al. 1998) and more generally, to a reductionist biomedical model (Good 1994).

Although my focus groups did not explicitly test for knowledge about donation, participants revealed their knowledge of the process through discussions and questions asked of me and each other. I did not find any significant difference among donor and non-donor participants in terms of factual knowledge about donation. Donor and non-donors both demonstrated a mostly comprehensive knowledge of the organ donation and transplantation process, neither group was familiar with deceased tissue donation, and neither group was aware that one could register as a donor outside of the DMV. As for the second aspect of the hypothesis—that an increase in knowledge will lead to an increase in donation behavior—other scholars have answered this question. Several scholars tested knowledge among different groups and did not find it to be a significant predictor of donation behavior.<sup>10</sup> So why does it still appear as a primary determinant in models of donation behavior?

Knowledge, attitudes, beliefs, self-efficacy...The different constructs of behavioral theory gloss over the importance of meaning and political-economy in driving perceptions about transplantation and, ultimately, donation registration behavior. As it relates to donation behavior, knowledge, it seems, is not that powerful. As for “myths” or “misconceptions,” these terms are so frequently and improperly conflated with general negative attitudes toward donation that they cannot be used as predictors of actual factual

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<sup>10</sup> Morgan, Miller, and Arasaratnam (2002), Reubsaet et al (2001), Bresnahan et al (2008), and Feeley, Tamburlin, and Vincent (2008)

knowledge. As discussed throughout this chapter, those beliefs so quickly dismissed by critics as “myths” are instead religious beliefs no less valid than any other, or commonly-held, cultural understandings of embodiment. None is worthy of dismissal as mere superstition. They are instead artifacts of structural violence.

These themes emerged simply by viewing OPO-produced PSAs, often with little prompting from me as moderator, suggesting that individual schemata used to process these messages are hardly divorced from cultural forces, but condensing those forces into a catch-all of “religion” as a barrier to donation is far too simplistic. Although donor and non-donor participants distinguished themselves by their reactions to the appearance of Biblical quotes, this is a false correlation. In the non-donor-exclusive focus groups, all participants were African-American. Their stronger affinity to the appearance of Christianity, their perceptions of the body, and their non-donor status itself are manifestations of the cultures and structures in which they were raised, just as the same can be said for participants raised in affluent households in Lexington County or participants growing up in Guam and Hawaii.

In the next chapter, I propose a new model of donation registration behavior that better accounts for the critical role that culture plays.

## CHAPTER 6

### CONCLUSION

#### 6.1 SUMMARY OF FINDINGS

In Chapter Three, I examined employed a systematic content analysis to discover the message frames used by OPOs to promote organ donation messaging. I found two frames dominated PSAs: “thank you for the gift of life” and “remembering the dead.” Messages were framed differently among other, less public-facing video types, suggesting that OPOs do promote multiple, competing messages. To examine the effectiveness of frames, I delved more deeply into PSAs. To determine how audiences reacted to different frames and reduce researcher bias, I used cluster analysis to identify different clusters of similarly-framed videos and selected videos to show focus groups.

In Chapter Four, I tested three hypotheses about framing and challenged assumptions about the effectiveness of framing strategies. I found that framing donation positively—by showing an example of a life saved rather than a death prevented—can be ineffective, as it actually commodifies the organ by turning the question into one of value versus the worth and need of the recipient. I found also that a negative framing of donation, exemplified by the Every 11 Minutes campaign centered around the loss of life for lack of donated organs, was actually the most effective advertisement shown. Finally, I demonstrated that when issues such as religion are introduced, a common framing technique of presenting arguments from an “expert” claim maker are problematic, as claims to expertise itself around both donation and religion are challenged by viewers. I

concluded by showing that although videos featuring underrepresented groups may be effective among viewers also belonging to underrepresented groups, racial and gender biases were not generally acknowledged. Interestingly, however, acknowledging bias about age appeared not to be taboo in the same way; overall, videos featuring older organ recipients were less effective than those featuring younger recipients.

In Chapter Five, I used the videos as a springboard to richer discourse within focus groups about donation and transplantation and discovered cultural and structural factors that influenced individual decisions to donate far more than health behavioral models employed in previous studies have suggested. Non-donors, represented within these focus groups exclusively by people of color, were keenly aware of structural inequalities within both the American system of transplantation and the medical establishment in general. Personal experience with donation and transplantation also contributed to reluctance to donate. “Barriers” to donation as commonly identified in literature, such as lack of knowledge or awareness or religious objections, did not appear to have any significant impact on individual donation registration decisions. Even “myths and misconceptions” such as organ theft rumors were born of mistrust of the medical establishment, not easily dismissed as folk superstition.

## 6.2 PROPOSED MODEL OF DONATION BEHAVIOR

Given these findings, some of which challenge more common health behavioral models, a new model for organ donation behavior is warranted—one that recognizes the complexity of both the political and economic landscape that shape an individual’s perception of healthcare, as well as the rich cultural meanings individuals and society attach to the precious, life-saving pounds of flesh that thrum within the living and are

extracted from the dead. The difficulty of proposing such a model to bridge the gap in donation behavior research between the public health, biomedical model and the postmodern, anthropological model is that it risks being either overly reductionist or so obtuse that its application to the field of health communication impractical. Therefore, I propose here a model for future thought without venturing to include an instrument for study.

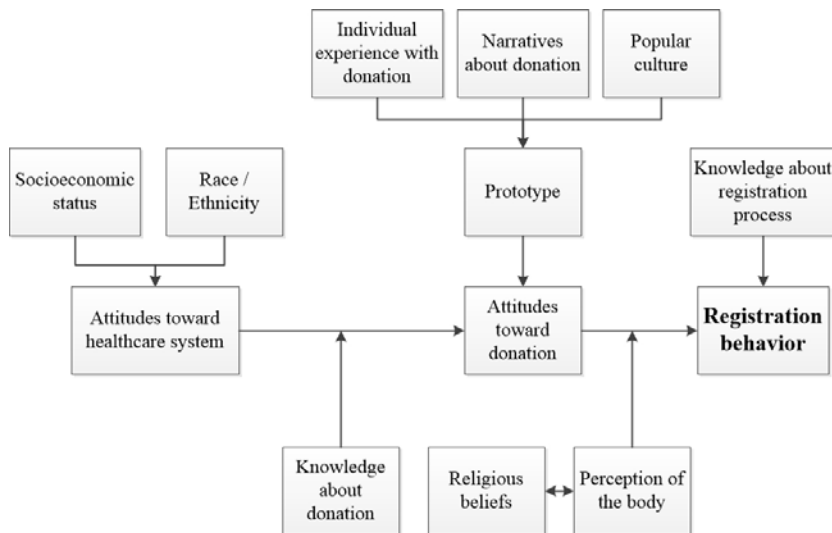


Figure 6.1 Model of organ donation behavior

According to this model, the primary driver of donation registration behavior is an individual's attitude about donation. While not revolutionary, I use "attitudes" here to encompass not an individual's description of donation as "good" or "bad" as has been used in previous research (Feeley and Servoss 2005; Feeley 2007; Frates, Bohrer, and Thomas 2006), but to describe the schema by which a person evaluates organ donation with regard to one's own self. Attitudes are created and molded by three primary factors: one's perception of the body (with consideration to the symbolic or real perceptions of embodiment of organs and one's beliefs about the validity of brain death); one's

prototype of donation as shaped by individual experience, popular culture, and cultural narratives (moral panics, urban legends, mass media); and an individual's attitudes toward the healthcare system. It is this last factor that, I propose, is the primary determinant of donation registration behavior; an individual's race or ethnicity and socioeconomic status play a key role in shaping these attitudes, though not—as has been proposed previously—by disproven assumptions about cultural beliefs, misguided religions, or lack of knowledge. Rather, factors such as race shape behavior because of a subaltern recognition of structural violence and inequality at play in the healthcare system.

Perception of the body is not a mediator, but a moderating influence to explain discrepancy between attitudes about donation and actual behavioral outcome. There are those potential registrants whose beliefs prohibit them from donating their organs, despite positive attitudes about donation. Knowledge about the *registration process* (not donation itself) helps explain registration behavior as well. Some participants in focus groups noted commonly-held assumptions that one could register as a donor only upon receiving or renewing one's driver's license. One non-donor participant stated that she had previously indicated her intent as a donor but, when she was not asked upon renewing her license, assumed (likely correctly) that she was not a registered donor. Recognition that one can register online, by mail, or at community events could increase donation registration behavior among individuals with positive attitudes about donation.

Fundamentally, however, a lasting improvement in attitudes about donation cannot be achieved without a matching improvement in attitudes about the healthcare system. Given the sordid history of the American healthcare system's treatment of



underserved populations, this is certainly easier said than done, and a sweeping overhaul of healthcare policy and practice is well beyond the influence of OPOs. Nevertheless, they possess the ability to reframe donation itself—not as a healthcare issue under the auspices of an unequal, distasteful healthcare consortium, but as one of community. In the next chapter, I will describe the successful—and unsuccessful—strategies OPOs have used to frame organ donation and suggest elements of an OPO campaign that could increase donation registration, despite the massive impact one’s attitudes about the healthcare system have on the decision.

### 6.3 COMMENTS ON METHODS AND THEORY

A question I struggled with throughout this study is whether or not the use of focus groups constituted interpretive anthropological study. After all, the traditional view of the anthropologist is that of the scholar integrating himself fully into a community through participant observation. Focus groups, to some extent, can be considered a more palatable version of veranda anthropology: dipping one’s toes into a cultural wellspring rather than jumping headfirst.

Certainly, focus groups have some clear downsides. Although I had met a few participants prior to the groups, I knew (and know) next to nothing about almost all of them, save for what they chose to reveal during those 90 minutes, yet ascribe to them thoughts and beliefs linked to broader sociocultural themes. Janet Smithson (2000) notes several challenges of focus group research, including the dominance of certain voices within the group, the effect of the moderator’s positionality on the interaction, and the tendency toward normative beliefs and values. As Smithson does, I must reflexively

analyze my own role as a moderator, and position the focus group research within a broader critical context.

By using a semi-structured format to the focus groups, I was able to achieve both goals of my research: recording audiences' reactions to different message frames and teasing out cultural factors driving donation registration behavior among participants. From an ethnographic perspective, I was dipping my toes, yes, but could still feel the temperature of the water. Consider the excerpts in Chapter Five. I deliberately did not frontload the discussion with questions about why someone is or is not an organ donor. Participants revealed these views willingly throughout the course of the groups, driven by not by the questions I asked, but by the discourse that emerged from allowing participants the freedom to express thoughts fluidly throughout the groups. Touchstones of cultural anthropology like race, religion, and structural violence became apparent through these discussions without more traditional ethnographic techniques.

What is problematic is trying to draw broad generalizations about culture or cultures without more detailed ethnographic research into a specific group. I cannot say for certain that African-American non-donors believe *this*, or that donors from Guam believe *that*. Even those conclusions I do draw should be taken within their proper context: I am a young, upper-middle-class, White, male, organ donor. Unquestionably, both my methods and analysis are biased, but I do believe my research to have elucidated reasons behind donation registration within a critical-interpretive context using a method that is both respectful of the people studied and unique in its approach.

There was a tendency toward normativity in these groups. I was upfront with participants in describing my research, and the videos—all OPO-produced—were of

course pro-donation. I was pleased to see that non-donors did speak up and voice their thoughts, even in predominantly donor groups. Even most of these non-donors described donation in mostly positive terms, especially early in each discussion. While this fits with previous research that finds overwhelmingly positive attitudes toward donation, I believe both donors' and non-donors' attitudes about donation are far more nuanced than most of the literature describes. As public health scholarship moves ever toward critical models of health behavior and explores social determinants of health, research about organ donation and communication will, too, open itself to the potential of placing donation behavior within its political and economic and historical context. Some scholars, even those operating outside of pure social science and within a more biomedical paradigm, have already begun such research (Jacob Arriola, Perryman, and Doldren 2005; Morgan et al. 2010)

When I first began this project, my intention was to conduct a participant-observation-rich ethnography of a health communication campaign. Upon my first meeting with Donate Life South Carolina, I realized that effort would be fruitless. If messages were created not by the OPO but by an advertising firm, even if I had access to that firm, it would not be an ethnography of OPOs, but of marketers. Instead, I changed my focus to be an evaluation of organ donation messaging within a critical context, hoping that I could learn not only messages' effectiveness, but also unravel some cultural mysteries surrounding donation registration behavior.

To the delight of the OPO that produced it, the Every 11 Minutes campaign was, it seems, *effective*, at least in the narrowest sense of the word. Diverse audiences seemed to prefer its message over most others, and even a majority of non-donors responded

positively. Bearing in mind that preference for one ad over others does not an organ donor make, this is good news, as I doubt the ad and its campaign—though flying in the face of previous research into framing effects—did not turn audiences off from donation as perhaps others (I’m looking at you, “Taxi”). I cannot, however, consider my work to be “evaluation” within a biomedical context. Participants were deliberately rather than randomly sampled, I did not properly control for variables such as race or ethnicity, and the fluidity of the focus groups defy quantification of results. As summative evaluation, it is pretty shoddy work.

As a *formative* exploration of cultural determinants of donation behavior, however, I believe it to be an important addition to both the anthropological and health communication literature. Anthropologists like Margaret Lock and Lesly Sharp have done an excellent job exploring different cultural perspectives on organ transplantation and brain death, while Nancy Scheper-Hughes brilliantly exposed the black market organ trade and its corollary in the American biomedical movement for a regulated market for kidneys. All three scholars situate transplantation within a critical-interpretive model, but on a global scale—across cultures and continents. My work attempts to answer instead a paradox on an individual scale: why would a person otherwise (allegedly) supportive of organ donation choose not to donate? The issues explored by these other anthropologists—medical mistrust, notions of embodiment, economic inequality—have a very real impact at the individual level, affecting how a single person may interpret a 30 second advertisement about donation.

This study also demonstrates the value of framing theory’s application to anthropological methods. Although social science disciplines have toyed with the theory

in the past (Bateson 1972; Goffman 1986), it has been studied primarily in what Hallahan (1999) refers to as “framing of situations” or the abstract construction of reality through discourse. Using framing theory to conduct a content analysis and study messages, I was able to remove some degree of researcher bias that would have permeated the study had I simply cherry-picked videos to show audiences. For lack of access to the message creators themselves, a clustered content analysis grounded in framing theory helped elucidate the variety of messages and competing meanings promoted by OPOs. Then by playing those differently-framed messages to audiences, I could see how that meaning changes from communicator to receiver—how political economy and culture shape the interpretation. To that end, I believe it is a solid complement to critical-interpretive anthropology and opens new avenues for research methodology.

As a scholar, I want my research to build upon the discipline of anthropology and further discourse about culture and meaning. As a public health professional, however, I want my research to be directly applicable to the field. I want to improve organ donation rates in South Carolina. I want to help OPOs do the seemingly impossible.

I had the opportunity during the course of this study. I received a call from “Brian,” my contact at South Carolina’s OPO, asking me to meet with a representative from a new organ donation foundation and present my research. The representative, I learned upon meeting her, was the founder of a fledgling organization created after her daughter passed away following an unsuccessful kidney donation. She and her husband were wealthy, and wanted to memorialize their daughter by creating a foundation in her name, chartered to increase organ donation registration among youth.

The founder, “Joan,” was as warm and passionate a person as I’ve met. They had approached the OPO because they wanted to invest their considerable wealth in a campaign targeting high schoolers and asked the OPO if they had suggestions. Brian, knowing I was researching effective messaging, asked me to discuss what I had learned. Joan was receptive and eager to hear. Then she spoke her piece.

She and her husband, also donors to a large university in a different state, had met a professional football player during a charity event at their alma mater. They explained to him about their daughter’s passing, described their foundation, and the player—moved by their story—agreed to appear in a public service announcement they would produce. He gave them the number for his manager and reserved a time for him to travel to South Carolina to appear in the advertisement. That day had arrived. That day was tomorrow.

“The trouble is,” Joan told me, “we don’t really have a script. We don’t know what works. Can you help us?”

I told her what I knew by that point—keep it positive, focus on life, rather than death. I gave her my number and told her that if she had more time, I would be happy to share my results with her and help her focus on a message that would resonate. We spoke for over an hour and, as I had to return to work, Brian escorted me to the door. Outside of earshot, he pulled me aside.

“Let me level with you. I asked you here because an opportunity like this to fund donation never comes around, and I am so worried that they’re moving too fast. We did the same thing, and invested all our money at once without knowing whether or not the campaign would work. We don’t want them to do the same thing.”

That night, Joan called me in state of panic. She told me that even the director of the video to be filmed, a longtime friend of the family, warned her not to move ahead. “She’s worried that we’ll get the player in here and not have a message, and that we’ll waste his time, and still not have a video.” I told her that I thought she was right. Wouldn’t it be better to develop a message and try to book the athlete again, later that year?

“Don’t you think a video featuring an NFL player from out of state might not be the best way to encourage donation?” I suggested instead that she herself, impacted so closely by donation, could tell her daughter’s story. We spoke for nearly three hours that night. At the end of the call, she sighed.

“I think you’re right. Brian said we should wait. The videographer said we should wait. You say we should wait. It’d be better to figure out our message and make sure we’re doing the best job we can. Will you tell me what your focus groups find out?” Of course, I assured her.

The next morning, I found an email waiting in my inbox. “Great news! The shoot’s back on! The videographer said she could just have him read a series of football catchphrases and statistics about donation, and then we’ll just figure out how to piece them together later!”

*This* is how donation messages are created. Joan’s passion, Brian’s passion, Steve’s passion, and the passion of those touched by organ donation and transplantation are what drive message creation for OPOs. Donation, like no other health behavior, pushes those benefiting from it to extraordinary lengths to repay a gift that can never be repaid, or to further a cause that even with a 100% donation designation rate would still

not be enough to match the growing demand for transplantable organs. So many of those indebted to their donors or grieving for those they have lost to disease see donation as a purely selfless act—a wholly good practice—and want others to see it through their eyes.

The problem is that their eyes are perhaps blinded to donation within its larger cultural context. They are not thinking of black market organs in Brazil or the Tuskegee syphilis experiments. They reduce the complex meanings associated with organs and hundreds of years of structural violence—some of which endures, both in the U.S. and abroad—to simple contradictions. If a preacher says the body is a temple, they say no, it's not. If a person of color says he is worried about medical abuses, they say don't be silly. And as Joaquin's cousin sits dying of kidney failure in Guam, they give us Steve Jobs as a figurehead.

I do not mean to imply that these OPO message creators are doing more harm than good, or even that these statements are somehow wrongheaded. What I do now believe, however, is that the solution to low donor designation rates is not a 30 second advertisement, no matter how well received it is by its audience. There is no one-size-fits-all advertisement, as no single video shown in the focus groups was universally liked or hated. This result should really come as no surprise; audience segmentation is a core principle of health promotion and communication (Slater 1995) and practically no health promotion movement or ad campaign intended for universal appeal keeps its eggs in a single advertisement basket. For every shocking, visceral "Truth" tobacco ad, there is an image of an empowered youth refusing to try tobacco.

South Carolina, like many other states, does not have the means to fund a wide-reaching campaign. Between 2006 and 2011, the annual state appropriations to Donate



Life South Carolina were slashed from \$350,000 a year that supported a staff of eight to seeing its \$100,000 appropriation vetoed by the governor and its staff reduced to only its executive director by 2013 (Haley 2013). Although the organization is buoyed by the work of a dedicated staff of volunteers, in-kind contributions by a well-meaning few cannot possibly hope to sustain a widespread media campaign segmented by audience; between 2000 and 2002 alone, the Truth campaign cost over \$324 million nationwide (Holtgrave et al. 2009). Fiscal year 2014 Federal appropriations for the Department of Health and Human Services for organ transplantation total just \$26,000,000 (Department of Health and Human Services 2013)—appropriations which must cover all operating costs, of which media outreach and donation promotion are just a part. Without a substantial increase in resources, reason dictates that the segmentation, reach, and consequent impact of a South Carolina donation campaign will be extremely small.

The utility of a television advertisement for organ donation is predicated on the assumption that viewing it will yield behavior change in the audience. If a wide enough net is cast, enough fish will be caught that the trawler pays for itself over time. If the evaluators' crystal ball is to be believed, while the Truth campaign can claim six-fold savings in future healthcare costs (Holtgrave et al. 2009), the economics of organ donation are less straightforward. Every registered donor does not a transplantable kidney make, and although kidney transplantation is cheaper to American healthcare costs over the lifetime of a patient than dialysis (Wong et al. 2012), the same cannot necessarily be said of the extraordinary costs of heart or lung transplants, that can range in the hundreds of thousands of dollars for the operation alone. Nor can the recipient be guaranteed a

postoperative lifetime of productivity that will outweigh the cost to the healthcare system and his family (Paris et al. 1993). Death is, quite simply, the cheaper option.

But I shall leave that dismal conclusion to the health economists; as a medical anthropologist, I am obligated both morally and professionally to suggest a community-based participatory model; luckily for me, that model may actually work. I suggest that (at least temporary) abandonment of a traditional health promotion campaign in favor of a targeted, community-based model will be more cost effective and have more success at increasing organ donation registration rates than any television commercial could.

The solution is more discourse. The solution is addressing the problematic history of organ transplantation and the current inequalities within the U.S. healthcare and organ allocation systems head on, acknowledging the legitimate concerns (not “misconceptions”) held by non-donors—particularly those belonging to underrepresented populations—and talking about them. To that end, these few focus groups I held across the state offered the first glimpse of what that discourse could achieve.

About a month after I held the group in which she participated, Tara gave me a call. “I wanted to let you know, Jeremy. Last weekend I went to get my license renewed at the DMV. They asked me if I wanted to register as an organ donor. Guess what? I said yes!”

## CHAPTER 7

### EPILOGUE: SITUATING DEATH

My mother died on a Friday. Her death came as no great surprise; after a yearlong battle with metastatic cancer culminating in liver failure, she passed away in a hospice facility. My father was with her in her final moments. He told me that he was keenly aware of the moment of her death. Her breathing became slowed and irregular, until her last breath was a deep, harsh rattle and she breathed no more. It was odd, he told me, but as he sat with her after her death, he could see that she was dead. Her skin became waxy and inhuman—something to do with the posthumous breakdown of fat or something like that, he heard from a nurse. But what was key was that she was dead, and he knew it. That was on Friday.

The doctor who served as medical director at the hospice facility was out on Friday, and would not return until Monday. For three days, the medical certification of her death sat on his desk, unsigned, while she waited in a drawer in the morgue. We could not begin funerary preparations because, legally speaking, Mom was not dead. Until that piece of paper was signed by a physician attesting to what Dad and the hospice nurses already knew, she was still technically alive. While we had moved through the stages of grief to acceptance, *society* was still stuck in denial.

Our grief was compounded not just by the failure of the medical establishment to remove her from this legal limbo for several days, but by the business of death that followed. The cremation society that handled her remains and charged with ordering her

death certificate failed to do so for more than a week. Until that ornamental piece of paper returned from the state's vital records office, riddled with typos listing her cause of death as "widely metastastatic ocular melenoma" [sic], my father could not begin processing her estate because, for lack of that piece of paper, the estate lawyer, insurance company, social security administration, and retirement system also viewed her as *technically* still alive. In the new business of dying, respiration and circulation don't mean shit; the veil between worlds is not spiritual, but bureaucratic. In ancient Greece, coins placed on the body after death allowed one to cross the River Styx and enter the next life. In modern America, you need notarized documents to do the same.

I use this story to illustrate the issue at the core of our troubles with organ donation. It further problematizes death. My mother was never declared brain dead, never kept alive artificially, and her heart never beat in another's body, and yet she was still left in a liminal state between living and dead for no reason other than the power to understand death has been taken from society as a whole and placed in the hands of medical and legal experts. Death is no longer a state of being but a process, and organ donation makes that process even more complicated.

When I first approached this study, I thought the issue with marketing donation could be solved by picking choices from a menu of dichotomies: narrative versus statistical information, real stories versus actors, emphasizing life over mourning death. Show some videos, code the responses, and at the end of the day we will be left with a formula for the perfect organ donation advertisement. This was a naive assumption. The issue, as always, is much more complex.

What I learned from these focus groups was yes, this video was better received than that video, and some people like this message, and some people like that message. The one universal thread, however, was the unease with which people view death—more specifically, their discomfort with attempts to give death meaning, and all attempts to market organ donation hinge on exactly that. Save perhaps for the noble soldier sacrificing himself on a grenade to save his comrades, death itself is meaningless. Life—and according to many beliefs, the afterlife—are what hold meaning in our culture. Death is the flip of a switch; death is the body, but is not the soul.

Organ donation advertising throws that into confusion, offering a kind of secular salvation. A person's life suddenly holds less meaning than the flip of that switch, when their organs and tissue save another's life. The person they were before their death, saint or sinner, is redeemed not through faith or good works but simply by dying. But donor and non-donor alike seem to reflect the same thought about death: it is itself an end. Whether one is a donor because he agrees "I won't need them when I'm gone," or one is an avowed non-donor because she worries she will be let go before her time, one views death as an end to life and the act of dying as one bereft of a higher purpose.

Perhaps the perfect organ donation campaign is one that has yet to be made, and perhaps never will. It is not one that trots doctors in front of the camera to explain how brain death *is* death, and it avoids preaching that one's biblical duty is to give one's organs to society. It does not attempt to canonize the teenager who died in a car accident or talk about living on in another. Instead, it simply acknowledges that people die—that you, too, will die...But in the business of death, as your paperwork is shuffled from doctor to lawyer as the medical and legal systems argue over whether or not and just how

dead you are, and the clergy situates you somewhere between this life and the next, a decision you make in life has significance. When your heart beats its last, whether you donate your organs or not—whether you lay eviscerated on a slab like Gerald or go up in a puff of smoke like my mother—you're just as dead. Them's the breaks, folks, so figure it out for yourself.

I am an organ donor. I promote organ donation. I believe organ donation is a good thing. When I die, if I donate my organs, it will not make my death any more meaningful than if they remained with me. But although I am not looking forward to it, I am comfortable with what death is and will leave the handwringing to the doctors and the lawyers. I do not believe the path to increased donation registration is to continue to promote contradictory messages of how the meaning of death changes with a heart stamped on one's driver's license. I believe the path forward is to improve relations between the medical community and those who have been historically wronged by it, to acknowledge and attempt to rectify structural violence and inequality, and to work with religious leaders to situate donation within their systems of belief.

As the funeral director escorted my father and me outside the cremation society's offices, a staff person walked out of the crematorium outbuilding to smoke a cigarette. Dressed in a splash-proof apron, coveralls, and elbow-length rubber gloves, with his gasmask-like respirator resting atop his head, he quickly hid behind a tree as soon as he saw us exiting, believing—I assume—that we would be devastated to be reminded of the nasty, messy process to which my mother would soon be subjected. Oddly, though, I found the sight comforting. In the mountain of paperwork and legalese, of euphemism

and empty sentiment, this man was the first genuine acknowledgement of the physicality of death.

It reminded me a bit of Gerald.

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## APPENDIX A

### VIDEO TRANSCRIPTS

#### A.1 CHARLES TILLMAN – WHY YOU SHOULD BE AN ORGAN DONOR

Charles Tillman: Hey, I'm Charles Tillman, Cornerback for your Chicago Bears. I've tackled a lot in my life, but nothing more difficult than waiting for my daughter to receive a lifesaving heart transplant. Thanks to the selfless gift of another human being, my wife and I get to hold our daughter each and every day. You too can help give someone a second chance at life. As a registered organ donor, you can help save the lives of more than 25 people. Be a team player. Register to be an organ and tissue donor at [donatelifeillinois.org](http://donatelifeillinois.org)

#### A.2 ORGAN DONOR MYTHS – RELIGION

Text crawl: Millions of Americans allow common myths and misconceptions to keep them from registering as lifesaving organ & tissue donors. We asked some Illinois residents to share their donation questions...And an organ donation expert to shed some light.

Title: Get the facts!

Title: Part 4 Religion

Angie: I've heard some religions oppose organ donation. Is that true?

Alison Smith (VP of Operations, Gift of Hope): Religion often plays a role in a family's questions about donation or an individual's questions about donation. And many people

think that their religion is against donation. In reality, every organized religion is in support of donation: Protestants, Catholics, most sects of- of Judaism, all are supportive of the role that donation plays in their religion. If you have a specific question about donation and how it fits into your religious beliefs, then obviously the best thing to do is to check in with your clergy, check in with the people who may have answers for you, but don't assume um without that information that donation is not a possibility.

Title: Get the facts!

### A.3 EVERY 11 MINUTES

*Sound effect of ticking clock. Names appear in handwritten scripts. View zooms out to reveal that names form the number 11.*

Narrator: Every 11 minutes, another person is added to the organ transplant waiting list. We'd like to ask for 11 seconds of silence for those who will die this year waiting for a transplant that will never come.

*Ticking clock stops. 11 seconds of silence. Names disappear one by one.*

Narrator: Register to become an organ and tissue donor today at [every11minutes.org](http://every11minutes.org).

### A.4 STEVE'S ORGAN DONATION VIDEO – THE CIRCLE OF LIFE

Title: The Circle of Life

*Fade into photo of a young woman. Black and white images of Steve.*

Steve: This is Kerry. Kerry was 17 years old. She was intelligent, she was athletic. Kerry was a star on her high school volleyball team. She was opinionated, stubborn, outspoken, and she had a smile that lit up the world. A little over eight years ago she was having dinner with her family in Iowa. Kerry brought up the topic of organ donation, telling her family she did not understand why someone wouldn't want to help someone else when

they were through with life here. Two weeks after that, Kerry's family had a tragic decision to make. But Kerry had already helped them with that decision. At the most devastating moment in their lives, Kerry's family reached out and saved my life. Kerry brought her big, beautiful smile into my life on April 8, 2000, when she and her family gave me both of her lungs.

*Black and white transitions into color.*

Steve: My name is Steve Fairhough. I am 48 years old and I've lived with cystic fibrosis all of my life. I breathe with Kerry's lungs. This is my story.

Steve: I was listed for lung transplant in September '97. My lung capacity at the time was around 10% of a normal person's. I was on countless medications. I was on oxygen around the clock and I required chest physical therapy. While I waited, every night before I went to sleep I said my prayers. I'd ask a lot of people up there for help. And I prayed that my future donor was enjoying their life. I waited on the list for almost three years and during those three years I had four false alarms, four times, four families going through four devastating moments in their lives, reached out and tried to save my life. Nowadays I wake up every morning, I stretch, and take a breath, and I don't hear my chest gurgling. It's been over eight years and I still walk around in complete awe of how this feels. I was back at work 10 weeks after my surgery. There's a double flight of stairs that goes from the trading floor to my office that I hadn't taken in 10 years. I didn't even go *down* them five years before transplant. Now, every chance I take, I bound up those stairs, two steps at a time and every time I get to the top, I smile, because I know who got me there. Thank you, Kerry.

A.5 DONATE LIFE NEW ENGLAND VIDEO – THE GIVERS

Title: A tribute to the givers

*Video of Mother Teresa. An animated ribbon outlines her face and moves through image to image: firefighters tackling a blaze, “free hot showers” sign, caretaker helping an elderly woman, another elderly woman reaching toward the sky, a police officer carrying a child, three people building a house, a man pushing a child on a bicycle.*

Narrator: What are they made of, the givers, who know instinctively that we’re all connected, who clothe the naked, who feed the poor. What are they made of, those who give their lungs so others can breathe, their eyes so others can see? What are they made of, for if everyone were made of this, then we would all be connected. We could reach out and save each other.

Narrator: Become a registered organ and tissue donor today. Visit [donatelifenewengland.org](http://donatelifenewengland.org)

#### A.6 DON’T LET ANOTHER CHAIR GO EMPTY – DANA AND HANK

*Shots of an empty green easy chair in a pasture next to horses.*

Dana: When you hear a diagnosis that... You have two to five years, it’s scary, I wasn’t ready to- to leave. My- my daughter had just gotten [cries] engaged and I wanted to be in her wedding.

Hank: Some young man said uh, when he signed up for his license, said I’ll be a donor. Well, that young man saved my life.

Hank: Don’t let another chair go empty.

Dana: Do it now.

#### A.7 TAXI SERIES 5

*Craig gets into a cab outside a hospital. The cab is covered with pro-donation bumper stickers.*

Leah: How are you, Craig?

Craig: I'm good, Leah! I'm just picking something up here. But you know, hospitals give me kind of mixed feelings about being an organ donor.

Leah: Why?

Craig: Well, I've heard they let organ donors *die*.

Leah: If *you* were a doctor, would you let *your* patient die?

Craig: Well, no, of course not, I mean I'd do everything I could to save a life.

Leah: Exactly. Doctors try to save every life.

Narrator: You can save lives too through organ donation. Call 1-866-YESUTAH or go to [yesutah.org](http://yesutah.org).

#### A.8 TYLER

Tyler: Hi my name's Tyler, I'm 15 years old. I've been golfing since I was about eight years old. This year I'm trying out for my high school golf team.

Tyler: When I was 11 years old I had bone cancer and it looked like I was going to lose my leg.

Tyler: I think life would be a whole lot different if I didn't have the bone transplant. I-I do have a scar on my leg, it goes from about here to here. The scars do come in handy when I'm talking to the ladies cause uh I tell them it's a shark bite h h

Tyler: You can kinda compare golf to life, you have your ups and downs and you just try to work for the best. Thanks to the tissue transplant I'm a regular teenager and a pretty good golfer.

Narrator: You have the power to donate life. Be an organ and tissue donor. To find out how, go today to [donatelife.net](http://donatelife.net).

Tyler: The tissue transplant gave me back my life.

#### A.9 NATIONAL DONOR SABBATH

*Sound effect of heartbeat. Fade in on electrocardiogram. Fade to images of prayer, compassion.*

Title: Heal the sick, raise the dead...Freely you have received, freely you give, Matthew 10:8

Title: What does it mean to give?

Title: What does it mean to give love?

Title: My command is this: Love each other as I have loved you, John 15:12

Title: What does it mean to give selflessly?

Title: Greater love has no one than this, That he lay down his life for his friends. John 15:13

Title: What does it mean to give life?

Title: God then used the rib that he had taken from the man to make the woman, Genesis 2:21-22

Title: You can give hope

Title: You can give compassion

Title: You can give life as an organ and tissue donor

Title: Thousands are waiting for a gift that only you can give:

Title: The gift of organ donation

Title: We pray for those who await the gift of life

Title: pray

Title: We celebrate with those who receive the gift of life

Title: celebrate

*Photos of recipients, donors shown next to quotes*

Title: Dillon, heart recipient: "Each day since surgery has been a blessing."

Title: Kathy, liver recipient: "I can't describe how grateful I am for my gift of life."

Title: Jackie, liver recipient: "Would you give to another, freely, to save their life?"

Title: We honor those who give the gift of life

Title: honor

Title: Janeen, organ donor: "Nothing loved is ever lost- and Janeen was loved so much."

Title: T.J., organ donor: "My husband and I were comforted knowing two children were alive because of T.J."

Title: Londell, tissue donor: "Londell always said, 'I want to be here when I'm gone.'"

Title: What does it mean to give thanks?

Title: Give thanks to Him and praise His name, Psalm 100.

*Donate Life logo*

Title: Give thanks. Give life.

## A.10 MASCOTS ON A MISSION – TRAINING DAY

Jingle: Mascots on a mission! Oh yeah.

Title: Welcome mascots

Title: March 15, 2010 – 0800 hours, Mascot Training Center

Trainer: You're an elite crew brought together across several agencies with one common goal: to take no prisoners, to have no mercy, and to TAKE THAT HILL!

*Mascots, including a heart, a liver, a bumblebee, and a dragon (among others) are standing in a line in a conference room*

Marketing executive: Yeah actually it's just uh donor mascot training, so, just uh

Trainer: As we speak, over 105,000 people nationwide are awaiting a lifesaving organ transplant. April is National Donate Life Month. So what am I asking you to do? Register organ donors! Yeah h h you're going to face some long days, so you're going to have to build up some stamina. You're gonna eat, breathe, and sleep donor awareness.

Trainer: Wha-wha-what not now! Gimme that! No blankies or pillows from home!

Trainer: We're gonna show you how to network, we're gonna tell you when to hand out a business card, when to ask for a business card, and where to stick a business card if you don't wear pants.

Trainer: Wha-what are you nodding at? Did I tell you to nod? Drop and give me 20, let's see what those teeny arms can do!

*The liver mascot drops and does pushups.*

Trainer: One! Two! Three! Four!

Title: It doesn't have to be this hard.

Title: Register as an organ donor today. Donate Life America.

Trainer (voice-over): Five! Use all that air going in there! You got all that air intake, use it!