

THE EFFECTS OF MEDIA DEPICTIONS OF ORGAN DONATION ON
TRANSPLANT PATIENTS

by

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Dedicated to my sister, Shoni, and the Lung Transplant Team at Vanderbilt who made all
of this possible.

Shut up and breathe!

ABSTRACT

When the topic of organ donation is broached on primetime television, more often than not, the depiction to follow is riddled with falsehoods that perpetuate long-standing myths and perceptions about the procedure. Sensational storylines are favored over factual portrayals, which can affect a person's willingness to donate. Studies have been conducted on the general population about their experience with inaccurate depictions and their responses gathered. In this thesis, I gain the insight of fellow transplant patients and the effect that these portrayals have had on them – the segment of the population these falsehoods affect the greatest.

A large portion of society will never experience life on the waiting list. During that wait, it is incredibly disheartening to see the very operation that will save your life grossly exaggerated and filled with impossibilities solely for ratings. Myself and transplant patients in Nashville, Tennessee provide a point of view on organ donation and transplantation depictions that is not usually heard.

TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION.....	1
Background.....	2
Myths.....	4
CHAPTER TWO: LITERATURE REVIEW.....	8
Media representations of organ donation.....	8
Audience studies.....	8
CHAPTER THREE: THEORETICAL FRAMEWORK.....	14
CHAPTER FOUR: METHOD.....	21
Sample.....	22
Protocol.....	22
CHAPTER FIVE: FINDINGS.....	23
Perception of transplantation as learned from television depictions.....	23
Fear of the transplant procedure.....	26
Representation of post-transplant life.....	30
Disappointment in abrupt ending of transplant storyline and lack of continuation.....	32
CHAPTER SIX: DISCUSSION.....	33
CHAPTER SEVEN: LIMITATIONS.....	37
CHAPTER EIGHT: CONCLUSION.....	38
REFERENCES.....	40
APPENDICES.....	44
APPENDIX A: IRB APPROVAL FORM.....	45

CHAPTER ONE: INTRODUCTION

On average, 22 people die each day while waiting for an organ (Facts and Myths, 2016). These patients are dependent on the act of organ donation. The notion of organ donation is not a subject broached often. Some feel that the topic is morbid, which corroborates a natural fear of death, and for others, it is simply not an issue that is addressed due to lack of awareness. Unless an individual has been personally affected by organ donation, or intently sought out information about organ donation, their idea of organ donation is formed by exposure to media (Morgan, 2007). More often than not, these depictions on television do a gross disservice to the public by consistently displaying storylines that center around the myths of organ donation. As the only introduction to information about organ donation, these television shows, which are often considered credible by viewers, formulate an idea of organ donation based off of a fictitious representation leading viewers to harbor negative views and opinions on the donation process, which ultimately leads to fewer organ donors.

In early literature, brains, head, limbs, and other body parts were the transplanted anatomy used in many science fiction films and novels such as *The Man with the Screaming Brain*, *Big Brain on Campus*, and *The Man Without a Body*, because it gave viewers a visual representation of the horror associated with transplantation attempts. Transplantation only occurred with external body parts so that all the gory details would be vividly illustrated for viewers. Frankenstein's monster was shown with a flat head and other recipients of transplants gone wrong displayed obvious disfigurement as a result of transplantation (O'Neill, 2006).

Current representations of organ donation undoubtedly have a negative effect. Because of current depictions, the majority of Americans, 59-75%, believe that an organ “black market” exists in the United States (Morgan, 2008). As well as believing incorrect information, in 2004-2005, there was no positive or accurate presentation of organ donation in all of popular television (Harbaugh, et. al., 2011). Television shows that showcase storylines surrounding abhorrent myths of organ donation serve no purpose and the only people profiting on these myths and depictions are television producers who see an increase in profits due to increased ratings. While many viewers see the sensational storylines as entertainment, the greatest harm is being done to the patients awaiting donors. As of March 14, 2017, approximately 118,000 people are currently awaiting an organ. Every 10 minutes, another person in need of an organ is added to the national wait list (unos.org).

Because of my transplant journey, I have encountered hundreds of patients directly affected by donation myths on television who would be eager to voice their experiences. This research will provide definitive answers about the effect of incorrect donation storylines by the population most affected. This view has yet to be published, and it could provide a great deal of insight to the damage actually done.

Background

Substantial evidence exists that prove that the depictions of organ donation, especially those that occur in such popular programs, leave viewers misinformed about such an important topic. For example, previous work mentioned above regarding the lack of positive or accurate presentation of organ donation in popular television resulted in specific research. The study was conducted to test the hypothesis that negative

representations of organ donation would reach vast numbers of American viewers with each broadcast. 155 million households viewed an episode containing negative messages about organ donation compared to 145 million households that viewed episodes containing positive messages. Further analyzed, 44 million households were sent the message that doctors “game” the organ donation system and 43 million households viewed an episode portraying doctors as vultures that eagerly await organ procurement (Harbaugh, 2007).

Organ donation storylines in television dramas are meant for entertainment, but actually serve as a basis for medical information that is most often incorrect. This study builds upon previous research in an attempt to delineate the effects of these depictions as seen by those who have no knowledge of organ donation as well as those who have received organ transplants.

The general representation of organ donation and transplantation in media has been far from accurate. The plots utilized in various television shows and movies reinforce the worst urban legends, myths and scenarios possible. The procurement of organs and their allocation have been shown as being corrupt and at times critical.

Even before organ transplantation became reality, it was synonymous with horror and science fiction and portrayed in movies and novels as a Frankenstein-type endeavor. Early portrayals of transplantation consisted of the transplantation of brains, heads and limbs. The concept of the “rebellious body” assembled by transplants as demonstrated in Mary Shelly’s *Frankenstein* propagated the role of the “mad” scientist (O’Neill, 2006).

Therefore, negative portrayals of organ donation are not a new concept. The consistent neglect for accuracy has been a running theme in organ donation representation for over a century.

Myths

From these tales of long ago, particular themes have persisted. One of the more resilient myths born from century-old horror stories revolves around the procurement of organs. In the novel, and subsequently successful 1978 film *Coma*, the plot involves a young doctor that discovers her best friend has been pronounced brain-dead after a seemingly minor surgery. She then takes it upon herself to look over the records of other patients and discovers a trend of young and healthy patients being declared brain-dead after simple surgeries (Crichton, 1978). In each case, the operation took place in the same operating room and after being declared brain-dead, were all moved to the same institute. After further investigation, she finds out that organs were being retrieved from these young and healthy patients for transplantation (O'Neill, 2006). This film is one of a plethora of fictional accounts of illegal activity regarding organ donation. An important aspect of these fictitious accounts is the portrayal of the doctors involved. The illegal procurement inevitably involves a discussion or debate between a higher ranking medical official and a naïve or otherwise young and inexperienced doctor. The elder medical figure is somehow portrayed as the enemy in the situation and the young doctor that was the culprit in the illegal action is left to carry on an ethically sound career (O'Neill, 2006). This exact scenario took place in an episode of *Grey's Anatomy* when a surgical intern severed a medical device and when confronted by the chief of surgery, the authority figure was viewed negatively (Quick, 2009).

Another prominent myth and the story most aligned with illicit organ procurement that has, and continues to, penetrate society is the myth of the “kidney heist” as depicted in the films *Dirty Pretty Things*, *Muggers*, *The Donor*, *Kiss Me Judas*, *The Broker* and many others (O’Neill, 2006). The myth usually consists of a healthy young man who meets an attractive woman at a bar, goes home with her, and is found by his friends in a hotel tub or bed bloodied with a freshly closed wound on his side only to discover that his kidney has been taken and sold on the black market. Some people may find this easy to discredit, but, for many, this urban myth that is consistently presented has become reality. “Even though the content and the show are long forgotten, the influence of the shows on people’s general sense of cynicism and suspicion about organ donation remain” (O’Neill 2006). The effect of the “kidney heist” myth is described as:

The belief that you can take an organ from anyone off the street and put it anywhere is extremely ignorant and extremely harmful. Urban legends of organ theft make transplantation appear gruesome and is a major cause of lost donations. Potential transplant recipients are dying because some asshole [sic] thought an organ theft story was entertaining (O’Neill, 2006).

The myth of the “Black Market” is often featured in various entertainment programming, in particular, legal shows and daytime soap operas. The majority of Americans believe that an organ black market exists (Morgan and Miller, 2002). The daytime television show *One Life to Live* played into public fears by featuring a lengthy storyline surrounding a chief surgeon that runs a black market for transplantable organs. He steals and sells organs for a significant period of time in the show and is eventually brought to justice. The extended nature of the storyline that took place over the course of several months likely added further justification for believing in the existence of medical corruption (Morgan et al., 2007).

A “Black Market” for human organs is sheer impossibility, especially in the United States, for a plethora of reasons. The intricacy of an organ transplant requires that the recipient is prepared at the same time the organ procurement begins. Organs are matched first by blood type and the presence of antibodies in both parties involved. Tissue typing of the donor and recipient must match in such a way that the potential of organ rejection is as minimal as possible, and the organ must correspond to the recipient. It is completely impossible that a “Black Market” organ seller would be able to match a recipient to a donor under any Earthly circumstance. Also, every single transplanted organ in the United States can be easily located and identified. Aside from the fact that the United Network of Organ Sharing has an account on both the whereabouts of the organ as well as each member of the transplant center in every single transplant program in the country, the repercussions of the exponentially microscopic event of transplanting a “Black Market” organ would be absolutely catastrophic for all parties involved (Morgan et al., 2007). There is also the matter of the thousands of dollars worth of immunosuppressant medications needed each day for the duration of the recipient’s life that would pose a major issue.

A recent issue in another country has added fuel to the “Black Market” myth. In China, the organs of executed prisoners were transplanted into citizens on the country’s transplant list; this is a practice that has persisted for decades (pbs.org). In 2015, Chinese officials stated that they no longer recover organs from prisoners and that the organ donation system operates solely on a volunteer basis. Unfortunately, this situation is often preceded by a salacious headline, which further exacerbates to belief of a “Black Market.”

Another commonly accepted myth about organ donation is the stealing of organs by transplant surgeons who secretly sell them / transplant to the wealthiest patients before others or the preferential treatment of wealthy patients. The public is undoubtedly oblivious to the national checks and balances designed to prevent these occurrences. They are also unaware that organs cannot be taken from anyone and then successfully transplanted into a specific patient. This myth gained prominence in the recent past when Steve Jobs, a California resident, was able to receive a liver transplant in Memphis, Tennessee, after a seemingly short wait period. This process can be explained by an act called double listing, where a patient can be listed by UNOS at two different centers, even in different transplant regions, for certain organs as long as they have the means to travel to either center when an organ match is made. The general population is not aware of that process, which is why the myth again regained traction.

CHAPTER TWO: LITERATURE REVIEW

Media representations of organ donation

While not intentionally engaging in a counter-campaign, media engages in the promotion of organ donation in ways which have far greater reach and impact than smaller campaigns can achieve (Morgan, 2009).

For a significant portion of a season of the television show *Grey's Anatomy*. Denny Duquette was a patient awaiting a heart transplant at the fictional hospital. In an incredibly dramatized episode, a wire to a device called an LVAD, a device meant to keep the patient's heart functioning, was severed by an intern in an attempt for him to advance on the donor list, effectively 'stealing' a heart intended and procured for another patient. Denny was wealthy and also had a relationship with a surgical intern. This event gave a great deal of credence to those of the belief that 'the system is rigged.' Solely based upon this episode, nearly 100% of the college students exposed to this episode believed that a relationship and / or wealth had an influence on transplantation (Quick, 2009).

Audience studies

While some form of accuracy exists in the depiction of organ donation, these rare instances are overshadowed by dramatizations. "Although news media coverage is usually accurate, focus seems to be directed toward human interest stories rather than scientific facts or advances. Conversely, entertainment media present compelling and coherent narratives about organ donation that revolve around medical, legal, and logistical impossibilities of the United States' current system of organ donation, procurement, and allocation" (Morgan, 2010).

Studies suggest that medical fiction is deliberately untrue or obscure so that the stories become more interesting and more dramatic. The complexity, ambiguity, and confusion surrounding the medical procedures portrayed leave the audience emotionally engaged but confused. It is not surprising that within the milieu of popular culture, representations of organ donation and transplantation are often inaccurate and sensational. A survey of 1143 people indicated that television was the major source of information about organ donation when compared to radio, press, magazines, family and friends (Quick, 2007). The very elements that make good fiction are the same that negatively affects people's willingness to donate (O'Neill, 2006).

Numerous studies have been conducted that show a correlation between media and storylines and their effect on viewers' decision making. Research conducted by Morgan (2007), in which frames of organ donation were analyzed, showed that "viewers acquired knowledge from the content of each drama, despite the fact that some content was inaccurate" (Morgan, 2007). In a study in which over 4,000 participants viewed primetime television shows with depictions of organ donation, it was found that viewers of other programs were "significantly more likely than viewers of *Grey's Anatomy* to know that one can sign a universal donor card and register in one's state" (Morgan et. al, 2009).

Because the media acts as a main source of influence on organ donation attitudes, television shows and other media sources can change perceptions (Yoo, et. Al, 2011). In a study conducted in 2011, Yoo et al., the Orientation1-Stimulus-Orientation2-Response model developed by Markus and Zajonc was used to determine if entertainment television acted as a mediator in formulating opinions about organ donation. (in this

model, orientation functions as a selective control of use of stimuli while it also mediates the effects of the stimulus on the responses. The model, therefore, provides an integrative theoretic framework for studying the antecedents and outcomes of communication activities (Yoo, 2006). Because media has been identified as a main source of influence on attitudes about organ donation, the O1-S-O2-R model can shed light on the cognitive process of how media can affect attitudes toward and behavioral intentions on organ donation. Knowledge about organ donation represents the O1 variable, predicting the ability to recall media content about organ donation (S), and attitudes toward organ donation (R), which affect behavior intentions toward organ donation. The S variable, media use, does not directly affect the outcome attitudinal and behavioral intentions, instead, it influences attitudes toward and behavioral intentions toward organ donation in an indirect manner by contributing to the myths or misunderstanding variables, which function as the O2 variable. One of the findings of this study was that participants who were able to recall television programs covering organ donation were more likely to have medical mistrust in reality (Yoo, 2011).

Medical mistrust not only had a significant negative effect on attitudes toward organ donation, but also a significant indirect negative effect on the behavioral intention of signing a donor card. The “entertainment miseducation” not only happens in direct ways, it can also happen through indirect mediation process, which has a negative effect on the intention of an individual to sign a donor card (Yoo, 2011).

Continuing to build upon the notion that viewers were making decisions about organ donation based on false depictions, further studies about organ donation and its depiction in media were conducted. In 2011, a survey of 429 respondents found,

“individuals who had negative opinions on organ donation frequently cited what they had seen on television shows, which contributes to the myths of organ donation, such as premature declaration of death and corruption of the medical system. The medical mistrust often creates fear among audiences, and this appears to be a factor that affects attitude in a negative way. In fact, a number of organ donation scholars believe that media portrayals of organ donation appear to contribute directly in creating many of these fears and myths” (Yoo, 2011).

With a plethora of information readily available, it is difficult to understand why, when television show runners, scriptwriters, and producers have the freedom to represent medical information, especially organ donation, in a factual manner, these television shows continuously depict sensationalized accounts or stories that represent the anomalies or outliers on the topic of organ donation. As the old adage states, “there is no such thing as bad publicity,” the sensational television storylines attributed to organ donation have a negative impact on one’s willingness to register as an organ donor or to donate the organs of a loved one (Morgan et. al., 2005). Research has shown that at least 90% of entertainment programs featuring organ donation contain false information (Morgan, et al., 2007). Storylines presented often mirror reasons for an individual’s reluctance to become an organ donor. Family members recite storylines from particular television episodes to justify their decision not to be a donor (Morgan, 2009).

Negative opinions about organ donation are almost always justified with information, stories, or images from the media, while positive opinions about organ donation were attributed to personal values and beliefs and only seldomly supported by stories about donors or recipients that participants heard or read (Morgan, 2005). Law

and Order, ER, The Learning Channel (TLC), the Discovery Channel, Jag, Touched by an Angel, Charmed, Dateline, USA Today, Oprah, and Good Morning America were specifically mentioned in the formulation of ideas about organ donation (Morgan, 2005). 'Return to Me,' 'Coma,' 'The Hand,' 'John Q,' 'Urban Myths,' 'Monty Python,' and 'Steel Magnolias' were movies that were listed (Morgan et al., 2005).

Viewers are very explicit about their fears that were supported by the media. Those fears were: premature declaration of death, belief in a black market for organs, corruption among doctors, corruption in allocation, and the transference of donor traits to recipients (Morgan et al., 2005). The television shows that were mentioned as the source of justification aired a significant time prior to this study, yet the myths depicted were long lasting.

An organization called Hollywood, Health & Society exists to assist television shows and writers in factually representing medical issues. The organization is based at the University of Southern California in the Annenberg Norman Lear Center. They are funded by the Centers for Disease Control and Prevention as well as other agencies and foundations (By the Numbers). While the organization touts the frequency of briefing writers on health topics in order to have depictions based in reality, it is obvious by the number of occurrences that there is some disconnect when it comes to organ donation. Entertainment media has become an essential tool in disseminating health information (Foss, 2014). With the influence that fictional depictions have, it is unfortunate that this particular health topic is not presented as closely to the truth as possible.

The continued negative portrayals are disheartening, especially to transplant patients and recipients. It is quite difficult to await a lifesaving transplant while listening

to others almost proudly exclaim their decision against donating originated from a television show. Not many people understand the risks that patients undertake pre-transplant. With an undeniable organ shortage, a waitlist can last years and the last thing that anyone awaiting a transplant wants to see or hear is inane objections to a lifesaving procedure.

My proposed research will offer the insights of those who have experienced the first-hand effects of organ donation myths, which is a perspective that has not been broached. Perhaps hearing direct responses from those most affected can bring about conversations regarding factual medical portrayals.

CHAPTER THREE: THEORETICAL FRAMEWORK

Walter Lippman defined the idea of agenda setting in 1922 as the notion that the news media, our windows to the vast world beyond our direct experience, determine our cognitive maps of that world. Public opinion responds not to the environment, but to the pseudo-environment, the world constructed by the news media (Bryant, 2009). The agenda setting theory was originally applied to news media, but the same notions can be applied to entertainment media.

Agenda setting is the result of a change in which items are more easily accessed by memory due to recent or frequent activation caused by the consumption of media messages. In first-level agenda setting, media outlets, by focusing on certain topics, tend to make knowledge about those topics more likely to be brought forth in working memory and, subsequently, more likely to be used when generating opinions about events and issues (Holbrook, 2005).

Individuals are inclined to exert as little cognitive effort as necessary in forming judgments; all relevant information in memory is not processed, rather convenient constructs are relied upon. This leads to a greater possibility that more accessible information will be used in constructing judgments (Holbrook, 2005). It bears noting that the activation of this information only assumes that the information is linked to a prior judgment in memory. The information does not need to be factual, only related enough that a linkage is formed (Holbrook, 2005).

Often, these linkages are based on prevalent attributes regarding the issue. These agendas of attributes have been called the second level of agenda setting to distinguish from the first level, which has traditionally focused on issues (Weaver, 2007). The

perspectives and frames employed by journalists draw attention to particular attributes of coverage and the perspectives can be very general (Weaver, 2007).

At the second level of agenda setting, the salience of attributes combined with cognitive cues represent the convergence of attribute agenda setting with opinion formation and change (McCombs, 2002). Attitudes and opinions aside, the reality created by the mass media have major implications for personal behaviors ranging from college applications to voting on Election Day (McCombs, 2002).

Attribute agenda setting, or second level agenda setting, deal with the reasons why people tend to support or oppose a particular issue. It is believed that the coverage of certain attributes by news media will become salient in people's mind (Kim, 2012).

Attribute agenda setting may also produce a priming effect. As certain attributes of an issue obtain more coverage, according to attribute priming, the audience gives more weight to the same attributes when deciding whether or not to support the issue. Therefore, the media tell people not only which issue to think about, but also how to think about that issue. This effect has important implications in shaping public opinion on a topic (Kim, 2012).

Framing and attribute agenda setting go hand in hand. Framing can be distinguished along at least two distinct dimensions: disciplinary origins and explanatory models (Scheufele, 2007). For the topic of organ donation, explanatory models of framing will be explored.

Framing research argues that "news frames function to suggest how audiences can interpret an issue or event. In fact, news frames can exert a relatively substantial influence on citizen's beliefs, attitudes, and behaviors" (Bryant, 2009, p. 19). With that

definition, it is unsurprising that frames appear to be related to other processes in news consumption and processing.

Framing is both a macro level and micro level construct. As a macro level construct, the term “framing” refers to modes of presentation that are used by journalists and other communicators to present information in a way that resonates with beliefs the audience may already have (Scheufele, 2007).

News stories about political issues or other events contain both information and frames. The ability to distinguish between the story elements and the effects they have has been an issue. The details about a particular issue, the details of the people effected, its costs, implications and so on can affect the audience’s beliefs about the issue and its treatments (Bryant, 2009).

A frame is what unifies information into an influential package presented to audiences. Often, frames are used as a necessary tool to reduce the complexity of an issue (Scheufele, 2007). “Frames build associations between concepts; information in a news story can cement the link, but it relies on a frame to build the associations” (Bryant, 2009). If the audience is presented an issue about which little is known, such as organ transplantation, the presence of information previously attained will form the basis for the link the frame represents. However, if a frame already exists to the audience, the presentation of a frame in a story can cause an effect. A frame effect does not happen solely because of the associations that are explicitly introduced, an effective frame needs no supporting argument to have meaning within some text. The effects can rely upon culture-based meanings, norms, and values (Bryant, 2009).

At their most effective, frames invite audiences to think about an issue in a particular way (Bryant, 2009). This notion can be applied to television depictions of organ donation; while the issue has an overarching theme of being a lifesaving procedure, the presence of frames with negative connotations influences audiences to associate those frames with the procedure in real life.

Framing contains many of the same elements of basic persuasion processes. Both assert that the presentation of content can influence attitudes in a predictable direction (Bryant, 2009). “Framing theory encompasses the origin, evolution, presentation, and evolution of messages” (Bryant, 2009). News frames can take the form of descriptions by journalists of people and other objects, the choice of elements of an event to be included in the news, words used to describe an issue, among many other things. Framing literature suggest that audiences are often not aware of the presence of frames and their potential influence. Framing effects are most apparent in what people think is important about an issue or what is relevant to understanding it (Bryant, 2009).

“To frame is to select aspects 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” (Bryant, 2009). The most effective frames are those that build connections to all four of those associations.

A number of studies have been conducted that examined how audiences receiving some news frame then interpret an issue. A number of other studies have demonstrated that how people think about an issue, including what they believe to be the most important considerations, can be influenced by exposure to a frame (Bryant, 2009).

Frames operate primarily in two ways: one, both an issue and the considerations associated to it can be introduced simultaneously in the body of a news account. If the receivers lack a set of linkages between the issue and its considerations, news framing can strongly determine how the audience understands the issue. Retention of associations between an issue and considerations after exposure to only one news article seems most likely to occur for an issue that is unfamiliar to audiences (Bryant, 2009).

The second way in which frames operate is by creating linkages between very familiar issues and preexisting beliefs, values, and attitudes. Evidence suggests that the extent to which frames tap into existing beliefs and impressions will influence their effect. Frames appear most powerful when they activate existing constructs. Receiving audiences will accept constructs that apply to an issue, but they are significantly more likely to do so when they have existing schemas for those constructs (Bryant, 2009). When a frame invites people to apply their existing schemas to an issue, the impact of that application depends on what it is in that schema (Bryant, 2009).

Frames in news media have been thoroughly explored throughout the decades and findings suggest that news frames are powerful and effective. Just as news frames can lead an audience to a certain belief, the same can be said for framing in fictional work.

“Fictional entertainment media also frames issues that define relevant considerations for viewers” (Mulligan, 2011). Fictional media are works of imagination that involve characters who interact with each other in a suspenseful, comedic, or some other entertaining plot. It is in these situations that organ donation is displayed. (Mulligan, 2011). Because fictional media is not based in reality, the fact that it might influence real-world beliefs often goes against conventional wisdom. Some suggest that

fiction cannot be appreciated, let alone influential, “without a willing suspension of disbelief, but it is presumed that even to enjoy fiction, viewers must find a way to buy into it by actively suppressing disbelief” (Mulligan, 2011). Fiction, as displayed in primetime television, has not been considered important enough to be the source of decision-making because it is created to entertain, not inform. Fictional portrayals on television have been shown to influence real-world perceptions of doctors and medical procedures. The perpetuation of a ‘black market for organs’ has been a storyline used on many television shows. Although the concept is false and is used in a fictional sense, this myth has been utilized so often that its depiction has led this falsehood to be a real-life belief.

Fictional entertainment media can convey socially and politically relevant messages through character development, dialogue, and plot (Mulligan, 2011). Topics presented in fictional media may give meaning to contestable issues to varying degrees. The context in which an issue is raised, the valence, tone, and implication of the character’s reaction to the issues offer a certain perspective (Mulligan, 2011). Like news programs, entertainment media use frames to help audiences conceptualize complicated topics by providing clues about the most relevant considerations. News media are constrained to be balanced in their framing of contestable topics such as politics; fictional framing does not need to be impartial (Mulligan, 2011). The creators of fictional media can create a context where an issue is interpreted in a particular way without concerns about an ethic of objectivity (Mulligan, 2011). The extent that entertainment media frames issues influences opinions in similar ways that news media frames issues. By

setting the context in which people think about an issue, fictional frames can affect how people perceive an issue and their opinions toward it (Mulligan, 2011).

The media structure dictates the way the public thinks about second-hand reality - one that can be formed by exposure to the media. Organ donation is an excellent example of a second-hand reality because unless an individual has been affected personally or intentionally sought information about organ donation, their idea of organ donation is formed by exposure to media (Morgan, 2007). Even when not directly sought after, previous media exposure may shape the overall medical process with frames previously presented (Foss, 2014). Media frames have common elements; verbal frames often revolve around myths, narratives, and metaphors that are understood and accepted and largely unquestioned by members of an entire culture (Morgan, 2007).

CHAPTER FOUR: METHOD

Based on information acquired through personal experience and extensive research, I will pose the question of how organ transplant recipients, both pre-transplant and post-transplant, have been affected by portrayals of organ donation in the media. I will also inquire as to the extent that perpetuating myths have affected their transplant journeys. Most recipients have incorrect knowledge about transplantation prior to meeting with a transplant program; the contrast between their thoughts and beliefs prior to transplant to their thoughts and beliefs after the experience would be interesting.

The answer to my questions will be obtained through focus groups consisting of organ transplant recipients and patients that are actively listed with UNOS and awaiting transplantation. Early focus group methodology was the design of Paul Lazarsfield, Robert Merton and their associates as an attempt to understand the appeal of radio messages (Brennan, 2012). The researchers focused on the discussion of the participants reasoning behind positive and/or negative reactions. “The goal of the focus groups was to gather information from audience members’ to understand ‘the group dynamics that affect individuals’ perceptions, information processing, and decision making (Brennan, 2012). Ultimately, the approach of a focus group led by Lazarsfield and Merton helped researchers understand the effectiveness of persuasive media messages (Brennan, 2012). By using a focus group to collect data, the atmosphere can lead to a very natural conversation allowing all parties to speak freely and have their voices heard. The informal nature, in addition to the dynamic of the group setting, allows the participants to share ideas without hesitation and perhaps arrive at conclusions that would not normally have been made.

Sample

The sample chosen for this research consists of patients at Vanderbilt University Medical Center and the Veterans Administration Hospital in Nashville, TN. These patients are either currently awaiting a solid organ transplant and listed with UNOS or solid organ transplant recipients. The patients are over the age of 18 and are willing to provide insight as to the effects that media depictions have or have had on them during their transplantation process.

Protocol

To conduct this research, I will be utilizing focus groups made up of current patients awaiting transplant or post-transplant. These groups will take place during prescheduled support group meetings. The participants will be asked to voice the ways that media depictions of organ donation have affected them. They will be asked about their encounters with friends and family who were against transplant / organ donation because of what they've seen on television or if they were fearful of needing a transplant because of what they've seen or heard about organ donation. The participants will also be asked to describe the ways that television shows can better represent organ donation and transplantation.

CHAPTER FIVE: FINDINGS

Transplant patients were asked about media depictions of organ donation and the effect they had on them during their transplant journey. Four focus groups, with sizes varying between 3 and 8 people each, were conducted comprised of transplant patients, both pre-transplant and post-transplant. A series of questions regarding organ donation and transplantation in the media were posed to each group regarding misconceptions. Participants were asked, “How do you think that the way that organ donation is portrayed on television influence viewers; are those influences damaging and why?” among others, and were encouraged to express their thoughts thoroughly. While many instances of dissatisfaction of organ donation on television were discussed, the most recurring topics throughout each focus group held were an overall dislike of transplantation representation, fear, and anxiety.

Perception of transplantation as learned from television depictions

The route from organ donation to transplantation is not the simple process that is illustrated on television shows. In most circumstances, a person will fall ill, or their underlying disease will progress, leading to the necessitation of a transplant of the failing organ. A great deal of tests are performed that are specific to that person’s transplant program, but they all have an overarching theme; doctors administer tests and procedures to determine if you are ill enough to need a transplant while healthy enough to endure the operation with minimal complications with a satisfactory quality of life. A score is determined from the aforementioned assessment; for example, in lung transplantation, this is called the Lung Allocation Score. This score determines your placement on the

UNOS list. In many television programs, doctors simply dial a phone number and order an organ as if it were fast food, and that is certainly not the case.

The person's health will decline while awaiting an organ, which will in turn increase their UNOS score. Ultimately, a match is made between the individual and donor, after even more testing, and approximately 12 hours later, the transplantation begins.

After a successful operation, that individual will remain hospitalized until they are stable enough for physical therapy, and upon completion of their transplant programs therapeutic requirements, they are free to cautiously live an exciting life.

This entire process is glossed over in nearly every instance of organ donation or transplantation in primetime television.

The great dissatisfaction of the representation of organ donation was the topic that dominated all four focus groups. The consensus was that "it just isn't real." Several aspects of the actual transplantation process were mentioned in particular: transplant work-up, post-transplant life and guilt that later manifests.

Many in the group were disgusted with the lack of attention that television shows devote to the actual process of being listed for an organ transplant. A 34-year-old recipient stated that the implied simplicity of a transplant is maddening. "Every one of these shows show a sick guy in a bed with the doctor over them telling them they'll need a transplant. It does not work that way and it makes me mad as hell."

A 62-year-old recipient added to this conversation,

When I first found out that I was going to need a transplant, of course, the first thing I did was google it. I looked up TV shows that had episodes with transplants and *House* was on the first page of the search, so I watched it. After I saw the episode, I thought the doctors were lying – it can't be as hard as they say it is! So many people watch *House*, they wouldn't lie about something like that! And of course, I found out *House* was completely wrong in every way.

A 58-year-old woman summarized the opinions of the group by comparing the coverage of other illnesses and transplant.

That's what I thought! Take breast cancer for example, my sister had breast cancer and what I saw on TV was pretty damn close to what it was; the chemo, the radiation – even getting sick after treatments was the same as my sister. So when I found out I needed a transplant, I didn't give a second thought that it wouldn't be close to real life. Man, when I tell you that I had not a clue, I mean it! When I got my schedule of a week's worth of testing that I had to do *before* they would even consider me, I was floored. I had no idea.

Prior to being considered for transplantation, there are a multitude of tests that must be passed in order to 'qualify' for the procedure. For example, for lung transplantation, pulmonary function must be within a certain window pertaining to that particular person. Antibodies must be identified in order to match the recipient with the best donor that will provide the least chance of organ rejection, and the patient must be able to walk a certain distance in a set period of time. Once these tests are completed, there are a myriad of other tests that are also needed: bone density, manometry, barium swallow tests and many more. It is only after these tests are completed that the patient is assessed by the board of their particular organ program, where their chances for survival

and quality of life are discussed, which leads to a decision of whether or not to transplant. According to the members of the focus groups, it is the absence of this process that upsets them the most.

As stated by an older heart transplant patient, “I watch TV, ok? When I was sick, I was glued to the recliner because I had nothing else to do, so I watched TV *all day*. I’ll admit, I watch *Grey’s Anatomy* because it reminds me of my daughter. Leave it to them, transplant is a breeze! You need a heart? Come on in, we’ll fix you right up! Nope. They got not one single thing right. It shouldn’t be allowed to be so wrong. I don’t watch [any] more.”

A 55-year-old recipient emphatically asserted, “People do not understand how hard transplant is. You don’t just get sick one day and decide to go get one. People *die* trying to pass these tests. People *kill themselves* when they don’t pass these tests. Show *that*.”

Fear of the transplant procedure

A reoccurring theme that was mentioned multiple times in each focus group was fear; fear of what may happen during the transplant and fear of what may happen after the transplant. It was said that when organ donation was a subject broached in storylines, media depictions often played upon a patient’s worst fear when confronted with transplantation. These instances were recalled in primetime television shows, but the depiction that brought about the most conversation was the 2007 film *Awake*. The film revolves around a man that experiences ‘anesthetic awareness’ and is awake during his heart transplantation. One of the focus groups consisted solely of heart transplant

patients, and the film is a common talking point during their support group, especially during the introduction of newcomers.

Other fears expressed were that of the procedure. Because primetime television shows rely heavily on drama, prior to their experience with transplant, the groups were terrified of the pain that they would experience. The television show *Grey's Anatomy* was mentioned as the source of this fear. In an episode of the TV show, an LVAD wire was severed, which was an unconscionable act according to the group. Every person in this group has had or currently has an LVAD, which is a left ventricular assist device that is surgically implanted to help the patient's heart work effectively. Prior to their experience, after viewing the episode soon after its air-date in 2007, the pain depicted in the episode nearly convinced them not to undergo the procedure. A 41-year-old patient, who vividly recalled this episode, says he questioned everything after viewing it.

“I won't lie, at the time, I didn't trust doctors or hospitals. I avoided them at all costs. I found out I needed a heart transplant in 2007 and after I saw this, I said *hell no*. I know it's TV, but there's some truth to that pain and I almost didn't come back.”

The primary source of information about the implantation of an LVAD and the incredibly painful side effects was the show *Grey's Anatomy*, particularly the episode “Losing My Religion” in which a patient with an LVAD was often seen screaming in pain while awaiting his heart transplant. This episode aired in May 2006, which was shortly before two heart recipients in the focus group were transplanted.

“I was listed at the time, I remember that, but I don’t remember the whole thing. What I *do* remember was seeing that and then [saying], “That better not happen to me!” I don’t even like mosquito bites, I do not like pain, no, sir.”

Another fear that was indirectly produced by the depiction of organ donation in the media was care immediately following the procedure. Studies state that 59-75% of the population believes some misinformed notion about organ donation (Morgan, 2008), and the patients interviewed were certainly among that statistic. It was mentioned multiple times that depictions of the surgery were frightening, but the lack of any depiction of after-care made the process more fearful. Some of the patients were afraid of the surgery because of what they’ve seen on television, but they were more afraid of life after the transplant. A recent lung transplant patient in their 40s, and an admitted avid television viewer, recalled organ donation storylines they’ve seen throughout their illness, “There is never any part showing you getting up trying to walk, the grueling appointments after the surgery, the medicine and those effects – nothing. They can scare you all they want about the actual surgery, but the scary part is after. Do they mention rejection at all?”

The group was upset at the amount of fear doled out by television shows for the sake of ratings. It is because of these falsehoods that many refuse to watch organ donation depictions altogether.

An older liver recipient stated, “I will not watch it, none of [those] hospital shows. I’ve been in hospitals, I don’t want to watch them. I know first-hand what they’re talking

about, what [do] I need to see it for? But my TV watchin' has changed, though. I like *Andy Griffith*, you know, fun stuff. My life's too serious, I don't need to watch serious."

For many of the patients, their fear of the procedure and life after lead to anxiety. Anxiety and fear went hand-in-hand in emotions expressed due to organ donation in the media. Many of these patients were placed on medication due to anxiety prior to transplant, and some said the media is partly to blame.

A 68-year-old recipient noted the abundance of organ donation related topics on television seen just as they were listed with UNOS. "Right when I got on the list is when I started seeing organ donation stuff on TV. And it was not good." Another recipient in their 50s chimed in with, "You know how you see a lot of your car after you buy it? It was the same thing when I got on the list. You know, they send you home with information, then you see it on TV, it can be a bit much."

One participant mentioned that after being listed, there was an abundance of television shows and news stories about organ donation that covered myths and misconceptions. They mentioned in one week they saw or heard mention of a donation myth. Upon hearing false representations, their feelings went from hopeful, because they were listed and closer to living a more satisfactory life, to anxious, because 'too many people believed the same incorrect fact.' This led them to constant anxiety about whether or not they would live to receive their organ when the number of people believing in organ donation myths and 'them not trying to save you if you're a donor,' were so great. They mentioned that this worry was prevalent in African American community, to which

they belonged, leaving them to need anti-anxiety medication to cope with their wait.

Other participants chimed in in agreeance to this notion.

Representation of post-transplant life

Discussion of this topic lead to the lack of representation of post-transplant life. Post-transplant care varies depending on the organ receive, but for at least the first six months, patients are all on the same antirejection medications, steroids, prophylactics, and all are to wear a mask during their most vulnerable period.

Upon leaving the hospital, transplant patients receive a book of rules to follow that detail the foods they are allowed to eat, vitals to track and side-effects from the medications. More often than not, a vast majority of transplant patients will gain weight and lose their hair; it is inevitable. Mood disorders also arise as well as other health issues. Once this period of time is passed, the medications are prescribed based on what genetically works for that person and follow up care is an absolute requirement.

Once the recipient reaches one year post-transplant, some restrictions are lifted, and that person is free to do as they please, within limits. Complications may arise, but transplant patients usually lead very happy and content lives from this point out.

Just as many of the members of the focus groups recalled their fears of the transplantation process being attributed to television programs, since there were very few, if any, representations of life post-transplant, many assumed that their lives would continue as they were before they fell ill.

As stated by a female lung recipient, “Depression, weight gain, mood swings, medication side-effects, losing your hair, diabetes, anemia; very few people come out of transplant pretty – it’s nowhere [on TV].”

Many of the members were upset at this aspect because they’ve stated that everything they’ve learned about transplant came from passing knowledge gained from television shows and media. Not one of them were prepared for how different life would be after receiving a life-saving organ.

A 56-year-old recipient stated, “There’s nowhere to learn that. TV doesn’t show it; you learn it by doing it. Sure, everybody heals differently, but if they can have a standard way of showing how organ donation and transplant work, they can have a standard way of showing what life is like after.”

Members of the groups stated that they were “left hanging” because the organ donation storyline suddenly ended. According to some, organ donation arcs included information, albeit minute, about the patient needing a transplant, and once the patient receives the transplant, the storyline ends.

A 59-year-old recipient stated, “Yeah, now what? The character got a liver, heart, whatever, then what? You’re coming back to the doc’s office, that’s for sure.”

An offshoot of this discussion led to a surprising inclusion of what the group members felt that was missing from current depictions of organ donation: guilt.

“There are two kinds of guilt that I’ve never seen on TV: the guilt you feel while you’re waiting for someone to die and the guilt you feel after surviving the surgery. You never say it out loud, but the time you’re on that waitlist and you’re

hoping you get that call soon, you're waiting for some mother to lose their child or some wife to lose their husband. That's what you're doing, you just don't say it. Then there's the guilt that comes from waking up and carrying on with your life. Some people don't wake up, and they tell us that when we go through everything with the doctors, sometimes something goes wrong and you don't wake up. But then you *do* wake up and you feel bad for your friends that didn't. That's hard to shake."

Disappointment in abrupt ending of transplant storyline and lack of continuation

Another aspect of organ donation representation that was not popular with the members of the focus groups was the abrupt ending of the storyline. One of the recipients, who happens to be the furthest out of their transplant, offered their opinion, "You know, that's another thing. Ok, we see you're sick and then 10 minutes later they're putting a heart in your chest. Where are his annuals? They may not care about those details, but at least once, show me a heart transplant patient a year out when he's lost his hair and he's gained about 70 pounds. (laughing) You don't get an organ and go skipping and live your life! Come on!"

A 41-year-old recipient added, "That's right! They get a new kidney and are never seen again – like your medical care just stops after the transplant. You know, they go, 'here's your kidney, have a nice life, we'll never see you again.' I'll tell you, I've seen my doctor more times in a year than I've seen my own family! It's nonsense."

The groups' most referenced television shows depicting transplantation, "Losing My Religion" from *Grey's Anatomy* and "Transplant" from *House M.D.*, the transplantation storyline lasted two episodes at the most. There was no continued information about the transplant or the patient in subsequent episodes.

CHAPTER SIX: DISCUSSION

Previous work has identified that organ donation depictions are highly inaccurate (Harbaugh, et. al., 2011). From these findings, it can be speculated that the false representation of organ donation is not beneficial to the transplant community. Current depictions can lead to feelings of fear and anxiety, leading to an overall disdain of organ donation representation. It has been suggested that current depictions may lead some to forego donation (O'Neill, 2006). While storylines are created for dramatic effect, which culminates in ratings for the television show, they also deplete the hope that pre-transplant patients have on receiving a lifesaving organ.

It is an understandable notion that individuals gain health related information from television and television programs. Studies have shown that medical dramas provide an important, and often primary, source of health information, and are used to persuade audiences toward healthier behavior (Brusse, 2015). In the case of the focus groups comprised by transplant patients, gathering their information about their impending operation – what it entails, the process and post-transplant life – is not a foreign concept.

As stated by a female recipient, “There was *School House Rock*, *Sesame Street*, even shows like *CSI*; those shows talk about real-life stuff! You know, it’s not stupid to believe TV, you can actually learn stuff, just not about transplant.”

The patients have gained knowledge from television at some point in their lives and assumed that the representations of organ donation / transplantation they viewed

were also correct. Unfortunately, after undergoing their respective procedures, they learned how incorrect their assumptions were.

When faced with a situation that has such a physical effect, such as transplantation, it is natural to recollect what is known and apply that knowledge. When these patients awoke in the ICU, they were scared and incredibly unprepared, and the fact that they felt fear is unsurprising.

The chief complaint of the focus groups - the inaccuracies of organ donation and transplantation depictions - was logical. The fact that television contributes to viewer learning has remained a central area of investigation in mass communications (Dutta, 2007). Also, evidence has shown that realistic and factual interpretations of health issues can be beneficial to viewers. Educational placements in entertainment contexts may serve as a reliable source of health information and are referred to as entertainment-education. It is an interventions strategy that is a promising technique for influencing attitudes, knowledge and behavior toward health-related issues (Brusse, 2015).

People seek out mediated information do deal with health problems, especially when the diagnosis is new (Zoller, 2006). After being newly diagnosed with a disease or condition, each patient spoken to admittedly paid attention to all organ donation / transplantation storylines they knew of. Because of these incorrect adaptations of the entire transplantation process, pre-transplant, the operation and post-transplant, each member had no idea what to expect during or after the procedure.

Much is desired when it comes to adequate and factual representation of organ donation / transplant storylines. When a medical issue is properly covered, valuable

information is gained by audiences. As seen in a 2015 study regarding the BRCA gene, those who viewed a television program covering the subject were twice as likely as those who didn't view the episode to not only gain information about the BRCA gene, but understand the risks that it poses as well as the prophylactic measures that needed to be taken to greatly prevent the occurrence of cancer (Hether, 2008).

The findings of this study can be associated with prior studies conducted on the reception of organ donation storylines on television (Morgan, 2010). The transplant patients that participated repeatedly stated that common misconceptions shown on television have led them to be afraid at some point throughout their transplant journey. Primetime television was the sole source of information the patients received about organ donation and transplantation. This shows the impact that television has and highlights the need for factual depictions; as stated in one of the focus groups conducted, the decision to believe what was seen on television regarding transplantation lead to the death of a patient.

This study sought to examine the ways that the framing of organ donation on television affect transplant patients, and based on the findings, the answer to that questions would be that organ donation depictions negatively affect transplant patients.

The media has been identified as a main source of influence on behavioral intentions on organ donation (Yoo, 2006). Negative beliefs and opinions are always justified by sensational depictions on television and in films (Morgan et. al., 2005). It can be interpreted from prior studies conducted that the media can be significantly influential

in decision making regarding organ donation. Perhaps if more factual information was presented to audiences, viewers will have the ability to form well-rounded opinions.

From the findings gathered in this study, it can be interpreted that current organ donation / transplantation depictions provide no discernable value. There are a number of people negatively affected by these depictions all for the sake of a dramatic storyline; this does not have to be. If television has the power to influence a vast audience into becoming educated on a cancer-causing gene through one accurate and medically factual episode, there is no logical reason that the process of transplantation and organ donation do not get the same representation.

Awaiting a transplant can be, to some, the most stressful wait one can experience. There aren't many people that can attest to this, but for those who have spent time waiting for a lifesaving organ - either relegated to one room and tethered to an oxygen tank or confined to a hospital bed because they can no longer care for themselves at home – every day awaiting 'the call' depletes that person's hope just a little bit. Each day that goes by, the body becomes weaker, which necessitates the need for the organ exponentially. To be confronted with a blatantly false depiction of organ donation written by someone whom may never experience life on a UNOS list can be greatly disheartening, to say the least. It has been suggested that negative depictions lead some to refuse to become donors (O'Neill, 2006), and, as a transplant patient, it can become worrisome that that organ may never come - for some patients, it doesn't.

CHAPTER SEVEN: LIMITATIONS

This work had limitations. This research excluded some transplant populations that may be larger and provide more informative insights. While this study was conducted with patients varying in age from 30 – 72, it could be suggested that more transplant patients of a younger age be researched regarding this topic with the inclusion of various social media. An increase in sample size would provide more definitive conclusions and may lead to better representation of such a sensitive, yet necessary, topic.

CHAPTER EIGHT: CONCLUSION

Beyond the fact that current representation of organ donation / transplantation storylines can lead to members of the general public to opt out of organ donation, the toll on those pre-or post-transplant deserves mention as well.

This work gave insight of how the framing and presentation of organ donation in current media depictions affects transplant patients. To do this, transplant patients were consulted and asked about their thoughts on how organ donation and transplantation in the media is currently represented and the effects it has on them as transplant patients. It was found that current representations are maddening and abhorrently distant from the actual experience of organ donation and transplantation to the point that they are no longer viewers of many television shows.

Current representations of organ donation and transplantation offer audiences sensationalism rather than scientifically factual information. Because the media is so persuasive, it would greatly benefit the greater community, especially the transplant community, to depict the topic accurately.

Because of the great influence that the media has on behavioral intent of organ donation, perhaps conscious efforts to educate viewers on the intricacies and positive outcomes should be explored. Portrayals based in reality will assist in the elimination of the gross inaccuracies that are presently taken as truth.

The number of patients dying each day while awaiting an organ is too great. If there is anything that can be done to offset the amount of lives lost each day, it should be

done. Organ donation and transplantation can lead to amazing results; for the sake of someone's loved one, this aspect should be depicted rather than falsehoods.

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APPENDICES

APPENDIX A – IRB APPROVAL FORM

IRB
INSTITUTIONAL REVIEW BOARD
 Office of Research Compliance,
 010A Sam Ingram Building,
 2269 Middle Tennessee Blvd
 Murfreesboro, TN 37129



IRBN001 - EXPEDITED PROTOCOL APPROVAL NOTICE

Monday, February 27, 2017

Investigator(s): Mazharel Rodriguez (Student PI) and Katie Foss (FA)
 Investigator(s) Email(s): mjr4b@mtmail.mtsu.edu; Katie.Foss@mtsu.edu
 Department: Media and Entertainment

Study Title: The effects that media depictions of organ donation have on transplant patients.
 Protocol ID: 17-2151

Dear Investigator(s),

The above identified research proposal has been reviewed by the MTSU Institutional Review Board (IRB) through the **EXPEDITED** mechanism under 45 CFR 46.110 and 21 CFR 56.110 within the category (4) *Collection of data through noninvasive procedures*. A summary of the IRB action and other particulars in regard to this protocol application is tabulated as shown below:

IRB Action	APPROVED for one year from the date of this notification	
Date of expiration	2/28/2018	
Participant Size	35	
Participant Pool	Transplant patients attending support groups at Vanderbilt Medical Center and the VA Medical Center	
Exceptions	Voice recordings are permitted.	
Restrictions	1. Mandatory signed informed consent 2. 18 years of age or older	
Comments	NONE	
Amendments	Date N/A	Post-approval Amendments NONE

This protocol can be continued for up to THREE years (2/29/2020) by obtaining a continuation approval prior to 2/28/2018. Refer to the following schedule to plan your annual project reports and be aware that you may not receive a separate reminder to complete your continuing reviews. Failure in obtaining an approval for continuation will automatically result in cancellation of this protocol. Moreover, the completion of this study MUST be notified to the Office of Compliance by filing a final report in order to close-out the protocol.

Continuing Review Schedule:

Reporting Period	Requisition Deadline	IRB Comments
First year report	1/31/2018	INCOMPLETE
Second year report	1/31/2019	INCOMPLETE