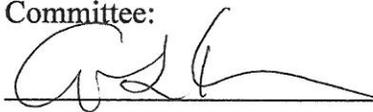


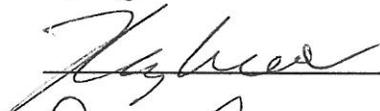
CONCERNS FOR SELF, OTHERS, AND FAMILIES: A QUALITATIVE ANALYSIS
OF FAMILY COMMUNICATION ABOUT ORGAN DONATION

by

Stephanie Dean
A Thesis
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A Thesis submitted in partial fulfillment of the requirements for the degree of Master of
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Bachelor of Arts
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Dedication

To Barbara Dean, my mommy and voice of reason; Chris White, without whom I would be lost; and Emily Hines, my best friend and favorite nurse.

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Abstract

CONCERNS FOR SELF, OTHERS, AND FAMILIES: A QUALITATIVE ANALYSIS OF FAMILY COMMUNICATION ABOUT ORGAN DONATION

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George Mason University, 2013

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Family communication about organ donation (OD) is seldom qualitatively studied despite its necessity when consent for donation is needed. This thesis includes the findings from a study in which seven families were interviewed and surveyed about their attitudes and intentions about OD and how the media plays a role. Families discussed OD through the facilitation of the researcher who asked five questions related to OD. The conversations were recorded, transcribed, and later coded for recurring themes. The surveys and transcripts were analyzed using a constant-comparative method. Data collected from the surveys were not analyzed statistically due to sample size constraints.

Families were assigned to one of three groups to measure the differences between two narrative forms. One group viewed a fiction narrative video while another group viewed a nonfiction narrative video. The third group was the constant. Participants were asked to complete a pretest, watch a video, complete a posttest, discuss OD with family

members, and complete a final posttest. Each study lasted no more than one hour. Family conversations lasted about seventeen minutes on average. Most participants were female, registered organ donors, had a bachelor's degree, and all participants were Caucasian.

Findings suggest that despite the trends in research that OD messages on television are mostly negative, participants agreed that most portrayals they have seen were positive and showed donors as heroic or compassionate. However participants struggled to recall specific OD messages. Rather, they were able to easily recall several other health campaigns such as Relay for Life and Red Cross blood drives even though they were not asked.

Family communication about OD centered on both the myths (medical mistrust and preferential treatment) and on concerns for self, others, and family. Many participants were more concerned that they would be able to make the right consent decision at the time of a loved one's death than they were with their own mortality. This important finding highlights the need for families to communicate effectively about their OD wishes. Limitations about sample size and recommendations for future research and practice are discussed.

Chapter One: Introduction

Currently there are over 74,000 active organ transplant waiting list candidates, but less than 10,000 available organ donors (United Network for Organ Sharing [UNOS], 2012a). Despite a 2005 Gallup poll finding that 95 percent of respondents support or strongly support organ donation (OD), only about 53 percent of Americans have registered as organ donors (The Gallup Organization, 2005). Furthermore, almost all (97 percent) of the respondents said they would donate a deceased family member's organs if they knew that he or she would have wanted to donate, yet only 53 percent of respondents reported having been told a family member's wishes (The Gallup Organization, 2005). Regardless of the good intentions of most Americans, research has shown that from 1997 to 1999 54 percent of families agreed to donate the organs of a loved one (Sheehy et al., 2003), and 57 percent consented from 2004 to 2007 (Brown et al., 2010), hardly an improvement over a ten year period. Today researchers recognize that one of the greatest barriers to OD – family consent – is largely a communication issue (Breitkopf, 2006; Exley, White, & Martin, 2002; May, Aulisio, & DeVita, 2000; Nathan et al., 2003; Rodrigue, Cornell, & Howard, 2006; Rodrigue, Cornell, & Howard, 2008a; Siminoff & Lawrence, 2002).

The striking difference between the number of available donors and the number of individuals on the transplant waiting list makes OD discussions imperative. However,

because of the sensitivity of the topic and the myths, fears, and general lack of knowledge surrounding OD, family communication about individual OD wishes is uncommon.

Though there are many campaigns encouraging families to discuss OD (see Donate Life New York State, n.d.; Lisa Landry Childress Foundation, n.d.; National Kidney Foundation, 2000; UNYTS, 2012), the social nature of entertaining visual narratives such as a television series may serve a facilitative function for family discussions. In fact, Saxbe, Graesch, and Alvik (2011) found that television viewing was primarily a social activity among adults and most often involved both parents and at least one child in a common area of the home.

Unfortunately, the messages about OD and transplantation in entertainment media are typically negative and sometimes frightening especially in the United States (Harbaugh et al., 2011). Television shows such as *General Hospital*, *The Bold and the Beautiful*, *Law and Order: SVU*, and *Grey's Anatomy* feature OD storylines frequently (Harbaugh et al., 2011). Moreover, research has shown that negative effects resulted from portrayals of breast cancer (Hether, Huang, Beck, Murphy, & Valente, 2008), organ donation (Morgan, Movius, & Cody, 2009; Morgan, Harrison, Chewning, Davis, & DiCorcia, 2007; Morgan, King, Smith, & Ivic, 2010; Morgan et al., 2005; Quick, 2009; Ye, 2009; Yoo & Tian, 2011), and bone marrow donation (Movius et al., 2010) on these television shows. Conesa et al. (2004) found that television in general is the most common medium for OD information used by the general public. Unfortunately, their findings further suggested that television has a negative impact on public opinion about OD. Based on these alarming facts and findings, this thesis focuses on individual

attitudes about OD, intentions to donate, and family communication regarding OD wishes as influenced by fiction and nonfiction visual narratives.

A Brief Introduction to OD Medicine and Research

The history of OD is brief, beginning in 1954 with the first successful kidney transplant between a living donor and his identical twin (United States Department of Health & Human Services [DHHS], 2011). Nearly ten years later between 1962 and 1963, kidney, lung, and liver transplants were recovered posthumously (DHHS, 2011). The late 1960s proved to be a significant decade in OD history and legislation with the establishment of the first organ procurement organization (OPO), as well as the first scientific organization for transplant professionals, the Southeast Organ Procurement Foundation (UNOS, 2012b; DHHS, 2011). Additionally, the Uniform Anatomical Gift Act established the donor card as a legal document. In 1977, the Southeast Organ Procurement Foundation developed an organ matching database they called the “United Network for Organ Sharing” (UNOS, 2012b).

It was not until the 1980s that OD became a social issue rather than an abstract medical procedure understood only by experts in the field. The 1980 Uniform Determination of Death Act stated that the “irreversible cessation of circulatory and respiratory functions or ... all functions of the brain” constitutes death ensuring the protection of potential organ donors. Further in 1984 the National Organ Transplant Act (NOTA) established the Organ Procurement and Transplantation Network (OPTN) to oversee the allocation of organs based on fair and equitable procedures (DHHS, 2011).

By this time UNOS had incorporated as a non-profit organization and two years later received the first federal contract to operate the OPTN (UNOS, 2012b).

Whereas the pioneers of OD in the 1980s were pivotal for establishing the legality of OD, the public health officials of the 1990s and on have focused on increasing the number of available organ donors. UNOS helped found Donate Life America, a non-profit organization dedicated to increasing public support for OD (UNOS, 2012b). Furthermore, the advent of the internet in the late 1990s helped practitioners spread the word and highlight the severe shortage of organ donors for those on the waiting list, including real-time public data on how many people were waiting for organs on the OPTN and UNOS websites (UNOS, 2012b). Currently there is a large and ever-growing body of literature in many fields including medicine and nursing, communication, media effects, and psychology suggesting that OD, as a social cause in particular, is more prominent than ever before (see Breitkopf, 2006; Brown et al., 2010; Exley et al., 2002; Morgan et al., 2007; Rodrigue et al., 2008a).

Although relevant research exists on the relationship between individual attitudes and intentions about OD and family communication, the theoretical foundations, methods, and findings are inconsistent across many fields. First, most studies found in clinical journals are quantitative in nature and employ surveys, sometimes asking participants to recall past experiences or predict future consequences. Communication and psychology studies utilized a variety of methods including focus groups and surveys; however they are not grounded on a particular theory, or they use a theory which has rarely or never been applied to OD. This becomes a problem when practitioners and

researchers seek solutions to real world OD issues because findings cannot be compared and evaluated equally across varying methods. Additionally mixed-methods approaches have yet to be utilized. Finally, despite the urgency with which researchers suggest the need for more family communication about OD, only a handful of studies have examined real-time family discussions.

The last point is most relevant theoretically and practically to this thesis. Many researchers have identified the problem – no family communication leads to lack of familial consent – and offered suggestions – campaigns to target families. Unfortunately, however, family communication about OD has not been carefully examined. One study to date reported on actual family conversations about OD and found that of the 21 recorded discussions, they varied in process, length on time, family communication styles, and attitude consensus. Thus, Pitts, Raup-Krieger, Kundrat, and Nussbaum (2009) concluded that not all families communicate or make decisions alike. As such campaigners should not encourage families to talk in general without a specific model in place; otherwise these family conversations could result in a lower likelihood of families consenting to donation. Until the dynamics of family communication about OD are examined more in depth, researchers should conduct descriptive studies of family conversations; otherwise practitioners would be remiss to follow such a vague recommendation as encouraging family discussion in general.

Rationale and Theoretical Framework

Few researchers have combined media effects, individual attitudes and intentions, as well as family communication in studies about OD. One applicable theory, social

representations theory (SRT), helps explicate the importance of studying these three concepts together. In a reciprocal fashion social representations inform and are formed by the behaviors of individuals (Castro, 2006). Briefly, social representations are cultural understandings of new or unique phenomena. SRT has been used in OD studies throughout both the United States and Australia. Each concept – media effects, individual cognition, and interpersonal communication – has a role in SRT. Nonfiction or fiction visual narratives used in this thesis represent the media and may have an impact in the formation of social representations. Individuals viewing media portrayals of OD may begin to form attitudes and beliefs about the phenomenon. When these individuals interact with others, social representations are formed or transformed. The most important role in SRT, interpersonal communication enhances individual cognitions and media impact by assigning shared meanings to phenomena (Morgan, 2009).

Additionally, transportation theory will be used to compliment SRT by examining the role of media on individual attitudes and intentions related to OD. Transportation theory suggests that individuals may be absorbed into narratives based on several extant factors which may lead to behaviors and attitude change. The vivid imagery produced by narratives has been found to influence health behavior and attitude changes (Green & Brock, 2000).

The formation of social representations occurs in a reciprocal fashion. For example, OD portrayals in the media influence individual cognitions which then influence family communication about OD; on the same token, family communication influences individual cognitions about OD. In other words, studies of phenomena such as

OD would benefit from mixed-methods approaches. The intent of this mixed methods study was to understand the media's influence on individual attitudes and intentions as well as family communication. The primary goal of the study was to understand the relationship between narrative form and attitudes, intentions, and transportation, as well as the influence of transportation on attitudes and intentions. Embedded in this study was a supplemental qualitative design to explore the influence of the media on family communication about OD. The particular approach – concurrent experimental embedded mixed methods design – was chosen because qualitative data would enhance the primary quantitative goals of the study. Furthermore, mixed methods were necessary because different hypotheses and questions were posed which required different data.

H1_a: Transportation into a positively-framed OD-themed episode of *Grey's Anatomy* will be positively associated with changes in attitudes about OD.

H1_b: Transportation into a positively-framed OD-themed episode of *Grey's Anatomy* will be positively associated with changes in intentions to become an organ donor.

RQ1: To what extent does the form (fiction or nonfiction) of an OD message influence changes in individual attitudes and intentions regarding OD?

RQ2: How do families draw on media to inform their conversations about OD?

RQ3: What topics emerge from family conversations about OD?

RQ4: What reasons do family members give for registering or not as organ donors?

Chapter Two: Literature Review

Social Representations Theory

Because the intent of this thesis was to understand media effects' influence on family communication as well as individual attitudes and intentions, SRT is an appropriate theoretical lens. SRT derives from psychoanalysis and was developed by Moscovici (1973) who posited that esoteric concepts normally discussed by psychologists and psychiatrists become lay theories which eventually find themselves in everyday interpersonal communication. A unique and underutilized framework, SRT helps to illuminate how society as a whole and the individuals within make sense of novel phenomena through communication and the mass media. Ultimately these social representations shape and are reciprocally shaped by individual and group behaviors. Specifically, social representations are systems of "values, ideas, and practices" which seek "to enable individuals to orient themselves in their material and social world" and second to provide a code (e.g., language) with which members of a group may communicate with one another to name and classify their world (Moscovici, 1973, p. xiii). Joffe (2003) simply stated that social representations are more or less "consensual understandings of phenomena, particular to specific social networks" (p. 60). Anchoring and objectification are the two processes involved in the formation of social representations.

Anchoring. Anchoring is a process whereby one social representation is incorporated into a well-known social representation through communication. Over time, the new phenomenon becomes familiar. There are five specific anchoring mechanisms discussed below. Naming is the most common way to assign meaning to a phenomenon. This process brings a phenomenon to light, gives it meaning, and provides an opportunity for interpersonal communication about the phenomenon. Emotional anchoring works similarly to naming, but involves emotional responses to a phenomenon such as fear, worry, or pleasure. Certain phenomena may invoke shared emotions among families and even entire societies. For instance acts of terrorism or school shootings tend to bring about shared emotions such as fear, compassion for the victims, and even anger among whole communities.

Thematic anchoring on the other hand deals with socially constructed, preserved, and often taken-for-granted ideologies. Some themes may be dialectical in nature such as life versus death in the social representation of OD. These dialectics may also be found through anchoring in antinomies, another mechanism of anchoring. Finally, anchoring by metaphors allows individuals to make sense of phenomena by thinking of them as something else. For example, in the social representation of OD, donors and transplant recipients are described as givers and receivers of the “gift of life.” On the other hand, doctors are sometimes labeled as “vultures” picking at the bodies of the deceased for organs.

Objectification. Another process in the formation and transformation of social representations is objectification, whereby a new or unfamiliar phenomenon is

materialized into something concrete (Morgan, 2009). In the social representation of OD, when an identifiable character is shown on television emotionally consenting to the donation of a deceased loved one's organs, that scene becomes an objectification of what it is like to consent to donation. It is much simpler for an individual to understand OD when he or she can see it happening – whether fiction or fact – than reading a pamphlet that describes the process. Emotional objectification refers to the existence of a strong emotional component. In *Grey's Anatomy*, a doctor fell in love with a patient waiting for a heart transplant, and in an extremely dramatic scene, she cuts the patient's LVAD wire to move him to the top of the transplant waiting list. The emotional components present in this scene objectifies OD as a corrupt process in which doctors pick and choose who receives organs which may evoke feelings of mistrust, anger, or fear. Objectification through personification on the other hand occurs when a specific person is linked to a social representation. For instance, Gandhi personifies non-violent social change.

SRT has been used with a wide range of methodologies and an even wider array of topic areas including immigrant rights (Van Dijk, 2000), antibiotic-resistant bacteria (Washer & Joffe, 2006), and organ donation (Harrison et al., 2011; Lauri & Lauri, 2005; Lauri, 2010; Moloney & Walker, 2002; Moloney, Hall, & Walker, 2005; Moloney & Walker, 2000; Morgan et al., 2009; Morgan et al., 2007; Morgan et al., 2005). Following the reciprocal nature of social representations, these studies discuss not only how communities shape social representations of phenomena, but also how the formation or transformation of social representations influences communities. Furthermore, these topics involve unique or new phenomena, another condition to SRT. Thus, the unfamiliar

and often uncomfortable concept of OD for the general public is a prime topic area to study under the SRT framework.

As mass media, namely news and entertainment television, increasingly portray OD both negatively and positively, the social representation of the phenomenon becomes more relevant. Harbaugh et al. (2011) found that the number of households viewing television featuring only negative or inaccurate portrayals of OD were double that of those viewing only positive or accurate portrayals (8.4 million vs. 4.1 million). Furthermore the emphasis of signing a donor card through the department of motor vehicles (DMV) at the time of renewal or when receiving an initial driver's license stresses the importance and urgency of OD (Morgan, 2009). Although many recent studies have focused on the existence of frames or myths in entertainment television portrayals of OD (see Morgan et al., 2007, 2010; Quick, 2009), few researchers have examined the potential of media to influence interpersonal communication (see Morgan et al., 2005 for a rare exception). Furthermore, most studies utilizing SRT have been conducted in the United Kingdom and Australia. For this reason, their findings may not be applicable to OD in the United States.

SRT's breadth encompasses "mass media framing, individuals' cognitions about the topic ... and interpersonal everyday communication regarding the topic" (Morgan, 2009, p. 33). Each of these three components plays a separate yet interconnected role in the formation and transformation of social representations.

Mass media. When it comes to OD, the majority of the public receives its information from mass media sources such as the news and entertainment television

(Conesa et al., 2004). Limited access to expert or medical information resources and the lack of trust in medical system means that mass media and interpersonal relationships, such as those with family or friends are commonly used by the general public for informational purposes.

Visual images and metaphors help individuals anchor the phenomenon to something familiar. For instance, OD portrayals in entertainment television tend to perpetuate the myths that many people believe such as doctors are vultures who steal organs or that the OD allocation system is corrupt. SRT makes no statement about the scientific accuracy of a social representation. Rather it is unfortunate that the social representation of OD leads to misunderstandings about OD processes and subsequently lower rates of consent for donation and registration as an organ donor. Moreover, individuals with little or no prior experience with a phenomenon are especially vulnerable to the influence of mass media. In fact, watching a narrative on television may be an alternative to direct personal experience (Joffe, 2003).

Individual cognition. In addition to the general lack of knowledge about OD as perpetuated by the media, entertaining visual narratives have the ability to influence individual cognitive responses. Language in particular is especially vital to the role of cognition in SRT. More specifically individuals use language to define and redefine social representations. The media may also use anchoring tactics like metaphor, hyperbole, and other linguistic devices to invoke mental images of more familiar objects to explain less familiar ones (Morgan, 2009). Additionally, framing helps assign meaning to social representations. For instance, we may understand the social importance of the

gay rights movement by framing it in terms of the Civil Rights Movement (i.e., something familiar to all).

Objectification in particular is useful in the role of cognition in the formation of social representations. Additionally, cognitions take place continuously before, during, and after the formation and transformation of a social representation indicating that internal struggles for meaning often entail a great deal of contradiction. Morgan (2009) explains that although there is consensus that most people believe organ donors are good people, dialectical tensions such as good versus evil and life versus death also exist.

Interpersonal communication. Whereas mass media depictions and individual cognition impact the understanding of phenomena, it is not until communication among individuals takes place that social representations are truly created. SRT posits that although social representations are expressed through individual cognitions, they are rather products of social interaction (Castro, 2006). Castro (2006) identified three communicative modalities – propagation, propaganda, and diffusion – based on analyses of the press which illustrate how cognition and communication perform simultaneously in the formation and transformation of social representations. Propagation is the integration of old and new ideas; propaganda is used to depict one right and one wrong set of beliefs; and diffusion is intended for dissemination of information regardless of stance on the issues. These modalities are evident in the dialogues of families discussing OD (Morgan, 2009). Pitts et al. (2009) discovered that some individuals discuss the merits of their family members' decisions to donate (i.e., propaganda), whereas others talk about OD facts and simply state their OD status (i.e., diffusion).

To date the Morgan et al. (2005; 2009) studies with 78 family pair dyads are the only published studies combining media depictions of OD and family communication. Although not explicitly stated, SRT is present in their citing of Moloney and Walker's (2002) SRT-based OD study in Australia. Transcripts of the 78 family conversations revealed that myths such as a black market for organs or medical corruption – myths that are rampant in media depictions of OD – were expressed as fears by participants. Moloney and Walker (2002) have found comparable results using focus groups in Australia.

The Role of Narrative

One important limitation of SRT is that it does not distinguish between types of media. Most OD studies grounded on SRT have utilized fictional narrative television episodes as stimuli. Narrative is an effective way to influence individuals and is used frequently in health behavior research. Hinyard and Kreuter (2007) put forth a broad definition when describing a narrative as a story with “an identifiable beginning, middle, and end that provides information about scene, characters, and conflict; raises unanswered questions or unresolved conflict; and provides resolution” (p. 778). This definition has been used in subsequent literature about narrative effects especially in the realm of health communication (Moyer-Guse & Nabi, 2010).

With this definition in hand, it becomes clear that we use narrative stories to learn and to teach ourselves and others. Narratives can be written, spoken, or viewed across a variety of media sources including radio, film, books, television, newspaper, and so on. According to Schank and Berman (2002), there are five specific narrative types which

may be used to fulfill specific communication goals: official stories – created by a group to explain their version of events; invented stories – fictional accounts; firsthand experiential stories and secondhand stories – as told by someone with direct experience or retold by another; and culturally common stories – generalized but pervasive to a culture. This study used both experiential and invented stories.

Historically, narrative effects research in the health behavior field has been limited to comparisons of non-narrative persuasion (such as using statistics to build an argument) to narrative persuasion (see Allen & Preiss, 1997; Baesler & Burgoon, 1994; Greene & Brinn, 2003; Slater, Buller, Waters, Archibeque, & LeBlanc, 2003; Slater & Rouner, 1996; Taylor & Thompson, 1982). Furthermore, although the health communication and psychology fields have seen an increase in the number of narrative-specific studies related to health belief and behavior change published, the various methods and definitions of narrative have yielded equivocal results (see Hinyard & Kreuter, 2007).

Finally, much of the current literature regarding narrative theory is based on overt persuasion and dual-processing models. Models such as elaboration likelihood model (Slater & Rouner, 2002) and heuristic systematic model (HSM) are useful in explaining persuasive effects when the recipient is aware of the persuasive intent (Hinyard & Kreuter, 2007). However, in studies such as the current one which used entertaining television episodes or videos not designed for the purpose of persuading the audience to take a certain action or think a certain way, these stimuli are not conducive to dual-processing models. Although entertaining narratives have been found to influence

audience attitudes and behaviors, audiences view these entertaining narratives for enjoyment and affective purposes, rather than cognitive purposes (Green, Brock, & Kaufman, 2004).

Transportation theory. On the other hand, transportation theory has proven to be more useful in the study of narrative persuasion than traditional dual-processing models. Green and Brock (2002) define transportation into a narrative world broadly as “a distinct mental process, which may mediate the impact of narratives on beliefs” (p. 324). More specifically, transportation refers to the extent a reader, viewer, or listener is absorbed or immersed into a narrative (Gerrig, 1993; Green & Brock, 2000). Participants were referred to as “viewers” in this thesis as they will be asked to view narrative videos.

Green and Brock (2002) put forth five postulates to transportation theory. The first postulate has three conditions. One condition posits that narrative scripts must not be rhetorical. In other words, the narrative must not attempt to sway the audience one way or another. Thus, messages such as advertisements, public education campaigns, and political speeches do not qualify as narrative. Another condition is that the narrative must evoke measurable “images that can be recalled, recognized, and responded to” (Green, & Brock, p. 321, 2002). The final condition to the first postulate is that viewers’ beliefs must be determined prior to measuring the effects of transportation.

The second postulate states that belief change occurs under the condition that transportation occurs. More specifically, the imagery alone in the narrative is not effective at belief change unless the individual experiences transportation. Finally, postulates three through five are related to susceptibility to transportation. Postulate three

posits that attributes of the viewer such as imagery skill (ability to create vivid images) determine the likelihood that transportation will occur. Fourth, the attributes of the narrative text or script such as artistry, fiction or nonfiction, or the structure of the narrative may affect the propensity for transportation. Lastly, the fifth postulate states that attributes of the medium such as the opportunity for participatory responses may affect the likelihood of transportation (Green, & Brock, 2002).

Furthermore Green and Brock (2000) have theorized that there are three effects of being transported into a narrative. The first effect of transportation involves the viewer accepting the narrative world as the real world, thus (temporarily and provisionally) losing access to the real world. Physically a viewer might be unaware of his surroundings such as others in the room. Psychologically the viewer might begin to accept facts presented in the narrative world as real facts, and because he or she cannot (or at least does not wish to) access the real world, it is possible that the narrative world facts can become embedded in the viewer's belief system. Furthermore, because transportation can keep viewers from accessing the real world, they may be incapable of considering logically the points made in a narrative and thus might not counter-argue.

Second, transportation can evoke emotions in viewers, regardless of whether or not the viewer knows that the narrative is fiction or nonfiction. These emotions can lead to identification which in turn can have a great impact on the level of transportation a viewer experiences. Green (2006) explains that aspects of identification such as liking, empathy, and similarity may affect the propensity for transportation and lead to belief changes. In other words, the more a viewer associates himself with characters in the

narrative the more likely he is to be transported and belief change should follow. Lastly, transported viewers may be somewhat changed by the experience of immersion into the narrative. Beliefs and attitudes can be influenced depending on the impact of the narrative and transportation of the viewer (Green & Brock, 2000).

Transportation theory research continues to expand and includes filmic and written narrative transportation. Findings are consistent with one another that transportation is positively associated with emotional responses and negatively associated with responses to the narrative content suggesting the strength of the theory (see Boyan, 2006; Caputo & Rouner, 2011; Dunlop, Kashima, & Wakefield, 2008; Green & Clark, 2012; Trujillo & Paluck, 2011). Banerjee & Greene (2012) recently found that the greater the transportation into a written narrative with an anticocaine message, the more positive the cognitive response and the more negative the affective response. In other words, highly transported individuals were more likely to report that cocaine use would destroy relationships or cause depression. On the other hand sadness associated with higher levels of transportation correlated with a lower likelihood to report that cocaine use was “very likely” to result in negative consequences which is contradictory with past research. However, affective responses strongly depend on the content and mood of the narrative, and considering the focus on physical and emotional loss in the anticocaine narrative, greater sadness is not surprising.

Fiction versus nonfiction. The fourth postulate of transportation theory regarding the fiction or nonfiction form of the narrative is especially important to this thesis. Fiction and nonfiction “can be used as means for convincing another. Yet what they convince of

is fundamentally different: arguments convince one of their truth, stories of their lifelikeness” (Bruner, p. 11, 1986). Slater (1990) hypothesized that nonfiction sources would have a greater impact on beliefs about social groups than fiction sources. Conversely, results indicated that messages labeled as fiction were slightly better at predicting beliefs than nonfiction messages but only when the social group described was unfamiliar to respondents (Slater, 1990). He suggested that fiction messages may lead readers to scrutinize the message less closely than nonfiction messages when the source is unfamiliar resulting in greater belief changes (Slater, 1990). In terms of transportation theory, perhaps transportation effects are present when a message is believed to be fiction rather than fact resulting in the unlikeliness of counter-arguing.

On the other hand, Green and Brock (2000) found that in some cases belief changes and transportation effects did not differ when the narrative was labeled as fiction or nonfiction. In one experiment, nonfiction narratives led to more story-consistent beliefs than fiction narratives but only for certain sources. The inconclusive findings regarding fiction and nonfiction labels of narratives suggest the need for more research. Furthermore, the Green and Brock (2000) experiments were based on written narratives whereas this thesis featured visual narratives. No research to date has examined the impact of nonfiction versus fiction messages as presented on television or in videos.

OD narrative studies. Several studies have examined OD-specific attitudes and intentions, as well as willingness to communication with family; however, less narrative-specific research exists. Of the limited literature available most studies employ surveys seeking recall of information (Yoo & Tian, 2011) or content analyses of television and

news (Feeley & Vincent, 2007; Harbaugh et al., 2011; Morgan et al., 2007; Quick et al., 2007). For instance, Quick (2009) examined the relationship between loyal and non-loyal viewers of Grey's Anatomy and their beliefs in various OD myths as presented in a series of episodes. Results were mixed such as the differences in beliefs of certain myths as well as attitudes toward OD and willingness to discuss intentions with family. Several limitations existed however, especially regarding the cross-sectional nature of the sample and the potential for other television shows to influence attitudes and intentions about OD given that several shows depict OD negatively.

One experimental study used social learning theory, transportation theory, and SRT to predict the role of entertainment television (specifically CSI: NY, Numb3rs, House, and Grey's Anatomy) on attitudes, knowledge, and behaviors of donors and non-donors (Morgan et al., 2009). Two hundred and ninety participants who had viewed one of six episodes of four different television shows which were aired as scheduled on network television were asked to complete a survey. Results suggested that non-donor viewers were more likely to become donors if the narrative encouraged donation, featured donor characters, or discussed the value of donating. In other words, the more vivid or emotionally involving the narrative the more likely viewers' attitudes were to sway in the direction of the episode.

Similarly, Morgan et al. (2010) conducted an experimental study and found that OD status was the strongest predictor of responses to negative OD depictions. This study was more firmly grounded in SRT than the previous study and sought to understand the influence of negative OD depictions on preexisting beliefs and attitudes as well as

subjective and descriptive norms. Although transportation theory was not used in this study it does not suggest that the participants were exempt from the effects of vivid imagery. Furthermore the use of SRT in both of these studies lends itself well to the combined media effects and family communication approach of this thesis as it highlights the intersection of media, cognition, and interpersonal communication in developing social and individual understandings.

Family Communication about OD

Unfortunately there is only one study to date that examined the effects of media messages on the content of family discussions (Morgan et al., 2005). Morgan et al. (2005) asked 78 family pair dyads to discuss their thoughts about OD and revealed that OD information received from the media manifests itself negatively in family discussions. The media in this case included entertainment (dramas, soap operas), news, and educational (TLC, Discovery Channel) television programming. Furthermore, according to Morgan et al. (2009) viewers who watched television episodes that portrayed OD positively (characters as organ donors, dialogue regarding the merits of OD) and viewers who were emotionally involved in the episode (transported) were more likely to decide to become donors after the episode.

Most OD specific family communication research is found in clinical, medical, nursing, and transplantation journals, whereas OD specific narrative media effects research is located in psychology or communication journals. Another study combined transportation theory and real-world discussions about cancer. Sharf, Freimuth, Greenspon, and Plotnick (1996) interviewed viewers of the ABC series *thirtysomething*

and found that following an ovarian cancer sub-plot, viewers engaged in peer discussions about cancer.

Although research about the media's influence on family communication specifically about OD leaves much to be desired, general research regarding OD and family communication exists. Family discussions about OD are attributed to attitudes about OD and intentions to donate, and lower instances of familial consent to the donation of deceased loved ones' organs (Rodrigue et al., 2008a). Instances in which the deceased is not registered, family consent is needed. Rodrigue et al. (2006) found that consent was significantly lower (26.7 percent) when the deceased's intentions were not known than when those asked for consent knew what the deceased wanted (73.3 percent). Siminoff, Gordon, Hewlett, and Arnold (2001) found that families who reported having OD-related conversations with family were more likely to consent to donation. In fact, according to Smith, Kopfman, Lindsey, Yoo, and Morrison (2004) OD discussions among families have been found to double the rates of family consent at the time of donation.

Currently, literature about family communication and OD features inconsistent methods and various theories. For instance, Afifi et al., (2006) used the relatively new theory of motivated information management to examine OD discussions to uncover what guides an individual's decision to discuss OD intentions with family and how that eventual discussion impacts attitudes toward OD and perceptions of families' attitudes. They found that issue importance, communication, and coping efficacy play a role in predicting the decision to discuss OD with family. Furthermore, following discussion

individual attitudes toward OD had improved, donation intentions had increased, and individual perceptions of family member attitudes and intentions were positive (Afifi et al., 2006). However, they did not qualitatively analyze the content of the discussions.

Smith, Lindsey, Kopfman, Yoo, and Morrison (2008) used HSM to determine the predictors of engaging in family discussion about OD and getting OD cards witnessed. HSM is similar to ELM and is used to predict cognitive responses to persuasion. They found that emotions were not important to engaging in family discussion but instead played a role in getting donor cards witnessed (Smith et al., 2008). As it turned out, emotions and cognition were not predictors of engaging in family discussion, but the willingness to communicate (WTC) scale was positively related to family discussion. In other words, participants who reported being open to discussion about OD were more likely to have engaged in discussion, though the correlation was not strong (Smith et al., 2008).

Research found in non-communication fields has examined the impact of family disagreement at the time of consent (Rodrigue, Cornell, & Howard, 2008b), beliefs and intentions regarding OD (Hyde & White, 2009), and perceived consequences of family discussion (Breitkopf, 2006) on OD consent. Another researcher conducted a content analysis of medical records and OD registries to determine the number of missed opportunities for donation (Christmas, Burris, Bogart, & Sing, 2008). Similar to communication studies about OD and family communication many clinical studies ask participants to recall conversations they have had in the past or to predict the outcome of conversations they have yet to experience. Few studies record and transcribe actual

family conversations about OD, with the exception of the Pitts et al. (2009) and Morgan et al. (2005) studies.

Pitts et al. (2009) recruited student participants to take home a packet for conducting the study from the comfort of their own homes without a researcher present. Participants were asked to record a family conversation about OD prompted by one open-ended statement, “Talk with your family about your OD wishes” (Pitts et al., p.416, 2009). Findings from the 21 recorded conversations suggested that families take various paths during their discussions including establishing consensus, as well as shifting conversational topics to ethical concerns and unanswered questions. In instances where disagreement arose, many families resorted to hypothetical scenarios to gain a greater understanding of family members’ beliefs and intentions.

Chapter Three: Methods

Mixed Methods Concurrent Embedded Experimental Design

Originating in psychology, mixed methods strategies can serve a greater purpose in efforts to understand and explain phenomena than quantitative or qualitative approaches alone (Creswell, 2009). Mixed methods research enhances the strength of a study by combining qualitative and quantitative forms. The concurrent embedded experimental mixed methods design used in this study consisted of one phase of data collection. Because quantitative data would not have been sufficient to explain the influence of media on OD attitudes, intentions, and communication, qualitative data was also collected. In other words, a secondary qualitative approach was used within the primary quantitative design to collect unquantifiable data. The rationale for this approach was that the qualitative data and their subsequent analysis provided a deeper understanding of the research problem that the quantitative data was insufficient at explaining (Creswell, 2009, 2011).

One strength of this strategy was that it involved the use of quantitative and qualitative designs to offset the weaknesses of using each design approach alone (Creswell, 2009). Furthermore, considering the limited resources available to me to perform an extensive qualitative study, the concurrent embedded design was appropriate (Creswell, 2011). To date, no OD studies have employed a mixed methods design. The

supplementary qualitative data provided a deeper level of understanding not found in previous quantitative research. For a diagram of the design, see Appendix A.

Sample

I recruited families using the snowball approach in which I asked my friends and family to invite their friends and family to participate and so forth. I also used recruitment flyers and emails to recruit students from George Mason University (GMU) and their families. The email was sent to all undergraduate students on the communication department listserv to inform potential recruits of the purpose of the study as well as requirements and benefits. I also asked GMU communication professors to email their students, and one professor posted the flyer on BlackBoard for all students to see. Furthermore, I was granted permission by two professors to enter their classrooms and briefly introduce myself and my study. I passed around a signup sheet so that interested recruits could give me their contact information which I used to email students additional information. A flyer was also distributed in the Johnson Center on the Fairfax Campus of GMU containing the same information as in the email but in a more visually appealing format. The compensation to participate in this study was a \$25 movie theater gift card for each family upon completion of the study.

Following the method employed by Pitts et al. (2009), after one participant was recruited, they were asked to invite two to four family members to participate with them in the comfort of their own home. Family members included relatives such as parents, grandparents, siblings, aunts, and other immediate family members as well as close family friends. All participants were over the age of eighteen and located in Northern and

Southern Virginia and Maryland. All participants, including the initial recruit and his or her participating family members, completed a personal experience survey to determine whether or not they had personally received or donated an organ. Those who answered yes to having received or donated an organ were to be excluded from the sample because of their direct experience with the process. However, this exclusion was unnecessary as none of the recruits had prior personal experience with OD.

The total sample consisted of seven families. One student from GMU and her family agreed to participate. The six other families were friends and colleagues of people in my network. One family lived in Maryland, two in Northern Virginia, three in Virginia Beach, Virginia, and one in Williamsburg, Virginia. Racially and ethnically the sample was homogenous, consisting of non-Hispanic, Caucasians. Half of the participants were in the 18-29 year old category excluding one participant who preferred not to answer. Most participants were female, registered organ donors, and had a college degree. The table below features sample characteristics.

Table 1
Sample Characteristics

	N (%)
Age (N = 20)	
18-29	10 (50)
30-49	5 (25)
50-65	4 (20)
65+	1 (5)
Ethnicity/race (N = 21)	
Caucasian	21 (100)
Gender (N = 21)	
Male	6 (28.6)

Female	15 (71.4)
Education level (N = 21)	
High school diploma/GED	1 (4.7)
Some college	5 (23.8)
Bachelor's degree	12 (57.1)
Master's degree	3 (14.3)
Organ donor (N = 21)	
Yes	13 (61.9)
No	8 (38.1)

Procedure

I interviewed seven families of three. Participants included mothers, husbands, wives, domestic partners, sisters, aunts, nephews, and a grandmother. Two families invited a friend to participate. A total of 118 minutes and 45 seconds of audio recordings were transcribed into 82 pages. The conversations ranged in length from 6 minutes and 44 seconds to 25 minutes and 8 seconds. The average conversation lasted 16 minutes and 57 seconds.

Each family interview was conducted in a room of their choosing at their own home. Most of the interviews took place in a living room. All participants sat comfortably in what I'm assuming were their usual spots when relaxing with one another. Most of the rooms had a television that was turned off. Participants seemed relaxed and open rather than tense which they may have felt had the study been conducted in a lab setting. One interview was conducted in the dining room while a participant continued to cook dinner. Despite her activity she was actively engaged in the conversation for the duration of the interview. Two interviews were conducted in kitchens which appeared to be the social meeting space of each house. Although I facilitated the conversations by asking five

questions related to OD, dialogue flowed freely and several families revisited the topic of a previous question.

The families were assigned to one of three groups – A, B, or C – on a first come first serve basis. For instance the first family was put into Group A, the second family into Group B, and so on. However, during Family 4’s interview I was unable to play the intervention video assigned to Group A or B so I placed them into Group C which required no intervention. Family 6 was assigned to Group A to maintain consistency in the group assignments. To protect participant confidentiality, I used an abbreviation for family role followed by the families assigned number (i.e., M4 is the mother from family 4; S21 is the second sister in the first family; see Pitts et al, 2009). Family numbers and group assignments are in the table below.

Table 2

Family Numbers and Group Assignments

Group	A	B	C
Family #	1, 6, 7	2, 5	3, 4

Group A received a fiction narrative television episode intervention framed to positively depict OD. Group B received a nonfiction narrative video intervention. Group C, the control, received no intervention. Prior to each intervention, all participants answered a pretest survey (see Appendix C) designed to determine baseline attitudes toward OD and intentions to donate his or her organs after death as well as the organs of

a deceased loved one. Following the intervention, participants from Groups A and B took a posttest (see Appendices D and E) to measure changes in attitudes and intentions related to OD as well as the level of transportation of each individual into the narrative. Group C, which did not receive an intervention, did not need to take the first posttest. Next, each group participated in a family discussion about OD under the guidance of the researcher who asked five open-ended questions. All conversations were audio-recorded for transcription purposes only using the voice recording application on my iPhone. Lastly, each group took a posttest to determine final individual attitudes and intentions about OD as influenced by the family discussions (see Appendix F).

Group A intervention. Group A watched an edited version of a season five episode of *Grey's Anatomy* entitled “There’s no I in team.” *Grey's Anatomy*, a popular prime time television drama on ABC, depicts health-related storylines in a multitude of ways. In every episode, the writers of *Grey's Anatomy* include health-related information. Unfortunately, this information is typically embellished for enjoyable audience consumption. For instance, it might seem to an average viewer of *Grey's Anatomy* with little personal experience with pregnancy, that pregnant women always experience a complication that puts both her life and the life of the baby in jeopardy. However, the occurrence of pregnancy complications is minimal compared to the number of live births (American Pregnancy Association, 2010). Due to its dramatic quality, popularity – average 16.8 million viewers per season – and variety of exaggerated health topics, *Grey's Anatomy* is a very appropriate choice of dramatic narrative to use in this study (ABC Television Network, 2005, 2006, 2007, 2008, 2009; Gorman, 2010).

Episode synopsis. Dr. Bailey is the leading surgeon on an extensive multi-transplant, multi-donation procedure nicknamed a domino surgery. There are six donors and six recipients for kidney transplantation. If one donor drops out of the surgery, then none of the recipients will receive kidneys. There are multiple dramatic storylines that occur between donors and recipients each of which ends with the donor making the final decision to participate based on the belief that it is the right thing to do. However, for this intervention, the episode was edited to only include the storyline of one family which pertains to OD.

A wife enrolls in the procedure for her husband, but is not a match to donate her kidney to him. Thus he must receive a kidney from a generous living donor. However for the domino surgery to occur the wife must still donate her kidney to another of the six recipients rather than her husband. Throughout the episode doctors, donors, and recipients alike thank a young woman who has consented to donate her kidney despite her not knowing any of the patients involved in the surgery. At first glance, it appears that she is a generous young living kidney donor with no connection to those involved. The episode becomes dramatic when the donor wife learns that her husband's "random" donor is actually his mistress of three years, and she threatens to not participate any longer. After Dr. Bailey communicates the severity of the recipients' conditions and the importance of donating her kidney, the donor wife decides to continue with the donation. She determines that not donating for the sake of punishing her husband for his extramarital affair would not be fair to the other recipients, thus she follows through with the donation and all recipients receive healthy kidneys. The edited version of this episode

concludes with a tearful interaction between donor wife, recipient, and recipient's family. After editing, the video was 11 minutes and 8 seconds.

An episode with a negative frame was not chosen because of its potential to influence participants' attitudes and intentions toward OD in the direction of the episode. In other words, if participants viewed an episode in which a doctor steals an organ for a family member, participants may believe this to be indicative of real world OD practices, which is not the case. An episode with a positive frame has been shown to reinforce existing positive attitudes and intentions and positively influence existing negative attitudes and intentions related to OD.

Group B intervention. The nonfiction narrative intervention given to Group B includes a video of the story of Caroline Henry-Glaspy, mother of deceased National Football League player and organ donor, Chris Henry. Shown in a chronological narrative format she begins telling the story of the night her son died in a car accident. She describes her emotions from that night and her thought process in deciding to consent to the donation of her deceased son's organs. The emergency room doctor on call the night of Chris Henry's death is also interviewed. Next the story, though still narrative and dramatic in nature, turns from one of sadness to happiness and second chances. The recipients and their families describe how their lives were changed by Chris Henry's "gift of life." The video concludes at the hospital where the donation took place with a first-time meeting between Caroline Henry-Glaspy and the recipients. Dramatic in nature with a clear beginning, middle, and end, this video contains all the elements necessary for a

study about narrative and media effects. The nonfiction narrative video was 8 minutes and 14 seconds long.

Narrative form. The form of each narrative was conceptualized as nonfiction or fiction. Group A received a fiction narrative intervention through an episode of a popular primetime medical drama. This narrative was considered fiction because all characters and situations were loosely based on real events or invented by the writers and producers of the show. Though the events that occur may have seemed real, they were not first- or second-hand accounts of real people or events. Nonfiction on the other hand was conceptualized as factual. The video documentary of the mother meeting her deceased donor son's transplant recipients was based on true events and real people. Schank and Berman (2002) called this type of narrative a first-hand experiential story, whereas the *Grey's Anatomy* episode was invented and considered fiction. Transportation theory states that narratives to be studied may be fiction or nonfiction. Although, early studies of transportation have shown that priming respondents that a narrative is fact or fiction had no influence on transportation, no studies have used visual narratives to test narrative form and transportation.

Family discussions. Following the pretest, intervention, and posttest, each family participated in a focus group about OD. According to (Creswell, 2007), focus groups yield the best information when interviewees are similar or cooperative with one another. Although families may have disagreements, the individuals within families are familiar with one another and may elicit information that the researcher could not. Furthermore, due to the limited resources of the researcher, focus groups are more advantageous than

individual interviews for completing the study (Creswell, 2007). One potential drawback may be the inequality among different generations or age groups in families. In other words, if one spouse is the primary decision-maker in the family, the other spouse as well as the children may be less likely to share open and honest feelings. However, in my family interviews all participants were equally engaged and actively participated in the discussion.

The questions used in this study were adapted from Morgan et al.'s (2005) eight open-ended questions and statements used to prompt family discussions about OD in their study of family pair dyads and media influences on discussions. For instance, Morgan et al. (2005) asked about worries and fears related to OD, which was reworded for this study as, "What are some issues that come to mind when you think about donating your own organs, or consenting to donating the organs of a relative or loved one?" Another question states, "What have you see, heard, or read in the media about OD?" The five family discussion prompts are in Appendix G.

Instrumentation

Each survey was a composite of several instruments across various studies designed to measure individual attitudes about OD, intentions to donate, as well as the level of transportation into a narrative. All instruments used a Likert-type scale response format, unless otherwise specified. Each instrument was based on previous OD studies, as indicated later.

Personal experience with OD. During recruitment, interested participants were asked to complete a personal experience survey to determine whether or not they have

personally received or donated an organ, or are on the waiting list to receive a transplant. A final statement sought to determine donor registration status of each participant. All statements were measured with a yes/no response. Those who responded “yes” to the first two statements regarding receiving or donating an organ would have been excluded from participating in the study; however, this was not an issue in this study. The registration status of each respondent was used in the final analysis as a descriptive variable. See Appendix B for the personal experience survey.

Attitude toward OD. The pretest was used to determine attitudes about OD and intentions to donate prior to any intervention or family conversation. Each group received the same pretest prior to their intervention. Attitudes were assessed using six likert-type statements measured from one (strongly disagree) to five (strongly agree) based on Morgan and Miller's (2002) adaptation of Goodmonson and Glaudin's (1971) attitude scale. The original scale contained 22 items measured on a five-point scale with a split-half reliability of .95 and a test-retest reliability of .94 (Goodmonson & Glaudin, 1971). Morgan and Miller (2002) shortened the scale to include six items measured on a 7-point Likert-type scale with a high reliability of .88; however, the current attitude scale uses measurements from one to five, based on the original and earlier adaptations of the scale. A final attitude score was not computed and scale reliability was not measured in this thesis; instead attitudes were analyzed.

Intention to donate. Intentions to donate were assessed with two likert-type statements measured on a seven-point scale from extremely unwilling to extremely willing. Each statement was based on Horton and Horton's (1991) willingness to donate

scale which sought to determine the likelihood of a respondent to donate his or her own organs as well as the organs of a deceased family member. Like the attitude scale, intentions were analyzed qualitatively.

Level of transportation. The original transportation scale developed by Green and Brock (2000) was included in the first posttest for Groups A and B to measure the major tenets of transportation theory such as emotional involvement with a narrative, lack of awareness of surroundings, and cognitive attention to the narrative (p. 703). The scale was originally developed based on written narratives and includes eleven general statements and four imagery items specifically related to the narrative being studied. The statements were measured with a seven-point likert-type scale from not at all to very much. The final scale had a Cronbach's alpha of .76 and Green and Brock (2000) noted that the alpha would not have been improved by eliminating certain items (p. 704). In their original transportation experiments, Green and Brock (2000) included character evaluations and found that greater transportation was associated with more positive character evaluations, which in turn have been found to influence attitude change (Eagly & Chaiken, 1993).

My study used an adapted version of the original transportation scale to fit narratives in video format. For instance, the statement, "While I was reading the narrative, I could easily picture the events in it taking place," was eliminated as it did not apply to viewing a television episode. The other original items were included in the modified transportation scale. Finally a section for character evaluations was included in each posttest for Groups A and B and were measured on four 7-point semantic

differential scales from bad to good, irresponsible to responsible, unpleasant to pleasant, and unattractive to attractive. The posttest for Group A included the characters Dr. Miranda Bailey (the surgeon in charge of the procedure), the mistress donor, and the donor wife. The posttest for Group B asked respondents to rate Carolyn Henry-Glaspy (mother of the donor), Brian Polk (kidney recipient), and Dr. John Green (donor's trauma surgeon). The final modified transportation scale data was analyzed qualitatively and used to supplement the family discussion data.

Analysis

For each hypothesis, the level of transportation was the independent variable and the individual attitudes or intentions were the dependent variables. All of these variables were interval levels of measurement. Because of the nature of the variables, I intended to perform a linear regression to determine if there were significant effects on attitudes and intentions as a result of the level of transportation into the narrative. Furthermore, RQ1 was to be assessed with a paired-samples t-test to determine if there were significant effects on attitudes and intentions as a result of the narrative form. Narrative form was a categorical independent variable, whereas the attitudes and intentions acted as the interval-level dependent variables. Unfortunately statistical analyses of the quantitative data would have resulted in unreliable findings. Despite the shortcomings of the sample size, the survey data were relevant and used to shed light on individual attitudes and intentions held privately compared to those attitudes and intentions individuals expressed openly to family members. Thus, the survey data collected for H1_{a-b} and RQ1 were analyzed qualitatively.

Research questions two through four were assessed qualitatively using the constant-comparative method introduced by Glaser and Strauss (1967). First all family discussions were transcribed manually using the recordings collected from each family interview. Next I replayed each recording and compared it against the transcript to ensure data accuracy. Then I read through all transcripts to familiarize myself with the data. Once I was fully immersed in the data I began highlighting transcript data relevant to the research questions and taking notes in the margins of each transcript. This initial open coding process enabled me to keep data unrestricted to particular categories.

Research questions two and four were related to two questions I asked families, so I analyzed themes related to these research questions differently than RQ3. RQ2 asked how families draw on media in their family conversations about OD. I was primarily interested to hear if any themes would emerge related to the media and OD, so I analyzed all transcripts thoroughly. However, most of the participants discussed media only after I introduced the topic. Therefore the themes which emerged are specific to the media question I asked during the family interviews. RQ4 was specifically related to a question I posed to the families about their decisions to register or not as an organ donor. My analysis for this research question was conducted using the responses received from that specific questions.

On the other hand, RQ3 was posed as a broad question because of the lack of previous literature about the content of family conversations about OD. I analyzed all responses to each of the five questions I posed to the families using open coding rather than pre-existing themes. After I discovered the main themes associated with RQ3 I

compared them to the Pitts et al (2009) study which is the only existing research using live family discourse. One main theme that emerged in both my study and theirs was hypothetical scenarios which is explained in detail in the Discussion chapter.

Finally using axial coding I analyzed how the themes were related to one another. With several labels and categories discovered, I determined commonalities among them. Closely related categories were combined. For instance, data revealed many participant concerns for self, others, and family members related to OD. Rather than three separate themes for each type of concern, I combined these categories into one theme labeled “concerns.” Interpreting the significance of the themes involved asking how they informed the way that the participants understood OD.

To add to the validity of this study I would like to clarify any bias I may have brought to the study. I am an organ donor and have volunteered at several local events to raise awareness for OD. My family and I have extensively discussed our donation intentions and wishes. Because of my knowledge of OD and familiarity with the literature about OD I only asked follow up questions to participants when I was unclear about the meaning of something said. I informed all participants that I would not be participating in their family discussions other than to ask questions to spark conversations. Some participants asked me questions about how the OD system works. I simply offered a broad overview of what OD is and referred them to unos.org for more information.

Another strategy I used to ensure internal validity aside from explaining my personal bias was triangulation. Although I analyzed all data qualitatively, I used different data collection strategies. Each strategy including surveys and family interviews

served as a check for the other ensuring that all data collected from each participant was consistent. For instance, all participant attitudes were favorable toward OD as indicated by their responses to the attitude portion of the survey and to the five questions I posed in the family interviews. To ensure external validity, I used thick description to present the results in the next chapter. Thick description is a commonly used qualitative research practice to help readers better understand the findings (Creswell, 2009). For instance, I provided multiple perspectives on the various themes and offered a description of the setting of the family interviews.

Finally, three techniques were used to add to the reliability of the study. First I have already described the settings of the family interviews and offered a detailed explanation of the focus for the study. Second I triangulated the data by comparing data collected using two different strategies as described above. Lastly, I explained the data collection and analysis strategies utilized in their entirety for this study.

Chapter Four: Results and Findings

My primary goal with this study was to examine the influence of narrative video form (fiction or nonfiction) on attitudes and intentions as well as the effects of transportation on attitudes and intentions. I posed hypotheses 1a and 1b to measure the effects of transportation into an episode of *Grey's Anatomy*. With research question 1 I was concerned with narrative form and whether or not it influenced individual attitudes and intentions regarding OD. The embedded qualitative part of the study design reflects research questions two through four in which I sought to discover the content of family conversations about OD. First I briefly discuss the hypotheses and RQ2. Then I report what I found throughout the family conversations. Major themes and subthemes are presented as well. The following results are organized in terms of each research question and hypothesis posed.

H1_{a-b}: Transportation will be positively associated with changes in attitudes and intentions.

As discussed in the Analysis section, the hypotheses were analyzed qualitatively rather than statistically due to the sample constraints. However, findings suggested that transportation had no influence on participants in group A who viewed an episode of *Grey's Anatomy*. In fact Family 5 which viewed the nonfiction video was the only family that was transported as determined by their responses to the transportation scale in their

posttest. Unfortunately, regardless of their level of transportation, Family 5's attitudes and intentions did not deviate from being favorable towards OD from pretest through the last posttest. This was true for all families including those who did not take the transportation portion of the survey. Thus, there were insufficient data to either support or reject H1_{a-b}.

RQ1: To what extent does the form (fiction or nonfiction) of an OD message influence changes in individual attitudes and intentions?

Similar to H1_{a-b}, RQ1 was also analyzed qualitatively. Based on responses from families in Groups A and B that received a narrative video intervention, form did not influence changes in individual attitudes and intentions. Furthermore, the form of the video did not appear to impact the conversations among each family. All participants had favorable attitudes toward OD and were very or extremely willing to donate their organs and consent to the donation of a family member's organs. These findings were not altered by either narrative form.

RQ2: How do families draw on media to inform their conversations about OD?

The second research question was posed to explore whether or not media influenced family communication whereas the previous research question and hypotheses were posed to examine the influence of media on individual attitudes and intentions about OD. Two families used the story of Mickey Mantle, a former baseball player and alcoholic who received a liver transplant and subsequently died, to better explain why they believed myths such as preferential treatment. However it was not until I asked families to discuss what they had heard, seen, or read in the media about OD that they

discussed media messages about OD. Their responses to this question fell into four themes including fiction TV and movies, portrayals and examples, naming other campaigns, and recommendations.

Fiction TV/movies. The most common answer participants gave regarding their experience with OD media was that they could not think of anything that they had seen. I could see them thinking deeply about this question to come up with at least one example, but it seemed as though this was the hardest question for the families to discuss. Participants were clearly taken aback to realize that they could recall very little about OD in the media. Eventually though each family was able to recall some form of media related to OD.

All families came to the conclusion that what they had seen was fiction television or movies. Three families were also able to recall real news stories or non-televised examples which are presented later. Family 1 determined that in their experiences, media portrayals of OD were always fictional. Their ability to distinguish between fiction and nonfiction portrayals of OD on television and in movies is of particular interest to this study. Despite the little knowledge this family had about OD, their attitudes and intentions did not change after viewing the fiction video. However, the myths they continually discussed throughout their conversation seemed more likely to influence their attitudes and intentions. Families 6 and 7 in group A were also not influenced by the fiction video. In fact when asked about OD portrayals in the media, they did not mention the video they had just seen which speaks to the lack of influence of this intervention on both their levels of transportation and changes in attitudes and intentions.

Conversely the families in group B, the nonfiction video group, both recalled the characters and the narrative throughout their discussions. Furthermore, they were more likely to recall nonfiction portrayals in the media than group A. For example Family 5 discussed several real-life news stories related to topics of death such as Terry Shaivo, Dr. Kevorkian, and Mickey Mantle. Unfortunately, however, the transportation effects varied widely from participant to participant and family to family in group B such as was found in group A. A larger sample size was necessary to determine transportation effects. Group C, the control, recalled both nonfiction and fiction accounts of OD in the media.

Portrayals and examples. Families 1, 3, and 7 from groups A and C each stated that OD is almost always positively portrayed in the media. A participant from Family 3 said that OD messages in her experience were portrayed “accurate[ly] and always in a positive manner. I’ve never seen anything that says, ‘Oh God don’t be a donor!’ or ‘Oh it’s terrible’ or you know?” Similarly a participant in Family 7 stated, “I think it only gets positive media. I can’t think of negative media.” Most interesting about the perspective of each of these families is the way they define negative media. To these families a negative portrayal of OD means that the message explicitly discourages OD. However, negative portrayals could also include inaccurate messages that further the myths about OD.

Two families mentioned the movie *Return to Me* a love story about a heart transplant recipient who falls in love with a man and they later discover that her new heart was actually his late wife’s donated heart. Family 3 in the control group recalled three episodes of *Grey’s Anatomy* including the episode I showed to the families in group A even though they were not aware of the other groups or interventions. This same

family also recalled a local news report about an employee at a local news station who was in need of a liver transplant. The local news was used as a conduit to encourage viewers to get tested to determine if they were a match to donate part of their liver to the employee. Even in this case where they were asking for help one could argue that it portrays organ donors as heroic, compassionate people because of the emotional appeal of the message. Most likely those that do get tested to see if they were a match are only doing so to help someone and save a life – both heroic and compassionate acts.

A participant in Family 6 recalled his experience as a fan of the band The Grateful Dead. The bassist for the band received an organ transplant and at every concert he reminds fans about OD and how it saved his life. The most interesting finding about the examples participants gave was that although most of them had to dig deep in their memory to come up with an example of OD they have seen, they all were able to recall at least one OD message that was always positive.

Naming other campaigns. More often than naming media portrayals of OD was the ability for the families to recall messages about other causes or health campaigns. The most commonly associated cause with OD is blood donation and the Red Cross. Three families related the Red Cross with OD and even questioned why the Red Cross did not promote OD during their blood drives. Other causes included COPD, Alzheimer's, Stand Up to Cancer, Susan G. Komen, Relay for Life, and bone marrow drives. I find it almost humorous that one participant was able to remember COPD campaigns before OD because of the far-reaching influence of OD on every citizen, more so than COPD.

Recommendations. Aside from naming other campaigns, many participants even offered suggestions about how to improve the OD message and make it well-known. For instance, a participant in Family 4 did not understand why OD registration occurred at the Department of Motor Vehicles (DMV) rather than at the doctor's office. She stated, "It's a little box you check! And I think that's a little off-putting for people." She also recommended that OD needs a walk similar to Relay for Life which would certainly bring more attention to the cause and even compel television news crews to report the story. Participants in families 6 and 7 each recommended that during blood drives, the Red Cross should ask people to register as organ donors based on the assumption that donating blood is as compassionate as donating an organ.

Whereas most participants said "they" need to do this and that, it is unclear who "they" are. A participant in Family 3 acknowledged that she was unsure who to hold accountable for such a responsibility and questioned whether or not the local organ procurement organization could do a better job of educating people.

RQ3: What topics emerge from family conversations about OD?

This research question was purposefully broad because little is known about what families actually discuss when they talk about OD. Three main themes emerged and several subthemes. They are displayed in the table below and described in detail in the following sections.

Table 3

Family Communication Themes

Main Theme	Subtheme
Myths and knowledge gaps	Mistrust in the medical system or doctors Preferential treatment and fairness of the transplant list Funeral issues
Concerns	For self For others For family
Hypothetical scenarios	Ethical scenarios Family scenarios

Myths and knowledge gaps. Myths and knowledge gaps arose throughout the conversations of six of the seven families even though I did not elicit responses about OD myths in any of my questions. Typically myths were discussed in a gossip-like format beginning with, “well, I’ve heard...” followed by an open conversation about participant fears. In fact, one conversation proceeded as follows:

S21: I feel the same way [about being a donor]. Although, I have heard of, you know, rumors of how they –

[1 turn omitted]

S21: ...if you’re not completely dead, there’s a chance they will take your organs if they think that you won’t make it. So I don’t know.

F1: That’s what I’ve heard too from doctors, so.

S21: Really?

The lack of knowledge about OD and mistrust of the medical system was also evident in this participant’s reason for not registering as an organ donor, “...I fear that um

I won't be treated with as significant priority or quality of care because of the simple fact that I am valuable as an organ donor upon death" (Family 7). Although he is not a legally registered organ donor he did express to his family his wish to donate his organs after death. This mistrust in the medical system myth was found in five of the seven family conversations. The two families who did not discuss medical mistrust shared other myths about OD.

Another myth expressed in three of the seven families was that preferential treatment exists or the transplant waiting list is not fair. One participant voiced his concern with the fairness of the transplant list in all but one of the questions I asked. On one of these occasions he stated, "That's my personal concern is that the organ – you know the list is fair. It makes sense. The people can use them. No one gets to jump the gun. I would really strongly be against that" (Family 5). As the conversation went on he introduced the story of Mickey Mantle, a former baseball player and alcoholic who died shortly after receiving a liver transplant. Another family concerned about preferential treatment also used Mickey Mantle's story as an example to justify their belief in the myth that influential or rich people get organs first.

Cosmetic issues arose in five out of the seven family discussions. In three of these conversations participants expressed that they did not know if an open-casket funeral would be possible after posthumous OD. When asked about any issues they can think of with donating their own organs after death, one participant responded:

S11: Umm, well if your family wants to have like a funeral for you and [pause]

have you all nice in a casket and stuff I don't think that would be possible. Well I guess it could. I don't know how organ donation works!

This statement was followed by friendly laughter by the other two participants in the family. Her concern with the cosmetic aspect of OD was clearly attributed to her lack of knowledge about the OD process. A participant in Family 2 also expressed cosmetic concerns, explaining that at his father's funeral, his father had an unappealing expression on his face. Based on his experience with open-casket funerals, his concern was not exclusively related to OD. Three families including one that expressed cosmetic concerns also discussed their wishes to be cremated rather than buried, thus eliminating the open-casket funeral issue.

There was only one family that did not discuss any myths about OD – Family 3 – which included two nurses. Currently one participant works in the intensive care unit of a hospital, while another has experience working in the burn trauma unit. Work in each of these hospital units involves situations in which death is a daily concern and so organ procurement organization representatives are constantly present either in person or via telephone. During their family conversation about OD, one participant asked questions about OD processes and procedures that were promptly answered by either the wife or mother. Because of their advanced level of knowledge about OD, myths were never expressed.

Concerns. Families frequently voiced concerns about OD in several ways. For instance some families used myths to explain their concerns. Others used hypothetical scenarios to help other family members understand their concerns. Concerns were

expressed in three distinct ways: for self, for others, and for family. Each of these subthemes is explained in detail below.

Concerns for self. Personal concerns were coded as anytime a participant expressed a concern or fear that directly affected the participant, and were expressed usually when asked about issues related to donating one's own organs or consenting to the donation of a loved one's organs. These concerns include the fears of being prematurely declared dead or not adequately cared for, or that the transplant waiting list is unfair (medical mistrust myth and lack of knowledge); concern that family will not respect their wishes; insecurity about consenting to donation for a deceased family member; and concern that OD remains a voluntary personal choice.

Medical mistrust myth and lack of knowledge. Four families expressed either a myth or their lack of knowledge as a personal concern. In these instances, the participants did not simply state the myth; rather they voiced their concern that the consequences of these issues could have a direct effect on them personally. For example, a participant in Family 2 continually mentioned that he wanted to be sure that he was dead before donation began and that the recipient was deserving of the donation. He said, "I just wanna make sure I'm dead first before you start harvesting my organs. You know what I mean?" His statement was followed by laughter from the other two family members which led to his feeling the need to explain why he felt that way. He proceeded to present several hypothetical scenarios in which he was prematurely declared dead so that a more influential or rich person could receive his organs.

Family 4 also expressed personal concerns about the organ allocation system. However, one participant stated her lack of knowledge about who is in charge of the national organ donor registry as a personal concern. I sensed tension in her voice due to her lack of control over the system as she asked several rhetorical questions:

GD4: I don't know enough about...how they dictate – that's the – that's the only thing. I mean I know there's a national registry but [pause] how do they decide if you know a child or somebody who's 85 – who gets it first? I guess that's hard – whose shoulder do you put that on? That's a big decision. And um that – unfortunately you can't just punch it in the computer and it'll give you an answer. That's – it's just a lot of grey area. I think that's probably the biggest thing. But it'll never go away because it's such a vital thing to life. I don't know.

Participants in Families 5 and 7 also voiced their concerns, while acknowledging their lack of control over the organ allocation system:

F5: I would want to make sure there's a strict order of hierarchy who gets it but uh [pause] obviously I can't do anything about it [laughing], but it's one concern. I would want to make sure I was in a state within a system that would abide by those kind of procedures.

Family respect for wishes. The importance of family communication about OD becomes apparent when families are approached for consent to the donation of a deceased loved one's organs. Two families expressed that they wanted to ensure their wishes were respected after death.

S21: It's important to me that my family like I mean like I guess it doesn't matter what they think, but at the same time it's an issue for me. Like if – if something should happen and they don't want me to be an organ donor then like that brings up some issues, but at that point they can't do anything about it.

Family 3, which included two nurses, discussed respecting wishes in several contexts. Based on their experiences as nurses, they've seen families refuse consent for donation regardless of the deceased's desire to be a donor. Clearly their experiences have had a significant effect on their personal concerns about OD. Each time these participants mentioned respect, they phrased it as "I hope my family respects my wishes." No other family phrased anything in this manner. Perhaps this family has a more realistic outlook on the process of consent since having seen it throughout their careers. The other families were not around OD as frequently as Family 3 if at all and thus were unfamiliar with the pressure and grief associated with OD which can inhibit families from consenting after a loved one has died.

Insecurity about consenting for a loved one. Another common personal concern dealt with whether or not they had enough information about their loved one's wishes when it came time to consent to donation. A very interesting exchange occurred in Family 1 when asked about their issues with consent as follows:

S11: ...It's not my decision to decide in the moment –

F1: For somebody else.

S11: – what to do with your organs.

S21: ...Even though I can't make a decision?

S11: You decide.

F1: It's not my choice.

From participant S11's tone, I could sense her frustration with potentially being charged with the responsibility to consent, but also her hesitance to make the decision for someone else.

Similarly, a participant in Family 2 stated, "I don't wanna do anything to you that you didn't want me to do to you." In other words, if he was not one hundred percent positive that his deceased relative would have wanted to donate and it was not on the deceased's license he would not consent. This hesitation to consent was common in six of the seven family interviews. The family of nurses (Family 3) did not express this concern most likely due again to the fact that they are confident in their ability to separate emotion from important decision-making such as during consent.

A participant in Family 4 was concerned with family conflict as a result of her hypothetical consent decision. She worried that if she made the decision to donate her mother's organs, her mother's surviving brothers and sisters would be unhappy with her choice and cause more grief which would possibly lead to legal issues. At the end of her statement she emphatically expressed, "I don't feel like it's a big deal!" referring to making the final consent decision.

Most participants who were concerned about consent stated that they would likely make the decision based on their own desire to help other people. Another participant in Family 2 expressed that he would apply a "personal bias" towards consenting to

donation. However, these statements were all based on hypothetical scenarios and therefore may not reflect decision-making when faced with a real-life situation.

OD is a voluntary, personal choice. The final commonly expressed personal concern was that OD remains a personal choice. For example, the exchange presented earlier between participants in Family 1 about being hesitant to consent to donation for someone else also relates to the personal choice concern subtheme. Although, some participants believed that family discussions about OD wishes were good, their stronger belief that OD is a personal choice tended to override their decision to actually discuss OD with their families. Three participants in three separate families simply stated that one's personal wish to donate organs is on your license and that renders family communication about OD unnecessary. However, this assumes that everyone who has a license knows that they can register at their local DMV, and it also implies that those people who either don't have or cannot get a driver's license cannot donate their organs. Perhaps for those three participants OD was something so familiar to them that they actually never considered alternative circumstances to their own.

Another aversion to family communication about OD was found in Family 7's conversation in which a participant stated, "I guess I always thought it was kind of a personal decision you – it's kind of like anything else. It's your life, it's your body, you shouldn't have somebody else making that call for you." She was referring to having never previously discussed OD with her family.

Family 2 on the other hand decided that the OD decision must remain voluntary rather than a legal requirement to protect individual religious freedoms. A common myth

found in other studies – religious objections to donation – were not discussed throughout the family conversation except for Family 2. However, religious objections were not a personal concern, but rather a concern for others.

Concerns for others. Families rarely expressed concern for others, but I felt it was necessary to include because it showed that people understand that OD affects everyone, even those they do not know. Above I mentioned Family 2's concern for others' religious freedoms. Although they clearly did not agree with using religion as a reason to not donate your organs after death, they recognized that there are many differing opinions regarding the issue of OD.

Families 6 and 7 raised the issue of the quality of their donated organs. A participant in Family 7 was gravely concerned with not giving “someone a busted up heart...I don't wanna screw someone over.” His other family member's followed with laughter but did not express opposition or challenge his position. A friend participated with Family 6, and she expressed concern over whether or not current technology and medicine was advanced enough to “clean [the organs] or something like sterilize them to get them where they're um fully functional for someone else.” Although this concern for others does show some compassion, I did not find any correlation between the themes “registering to help other people” and “concern for others”.

Concerns for family. Concerns for family were coded as anytime a participant expressed an issue that would directly impact a family member or loved one. These concerns included peace of mind and power and conflict.

Peace of mind. Oftentimes participants would express concern that after they died, donation would take place without their family understanding why. This was a common reason for agreeing that family communication about OD was vital. A participant in Family 1 stated bluntly that her family needs to know that she was an organ donor “so that you know if it’s something that does happen to you, they’re not just like, ‘Oh why are you chopping her up into little pieces?’” Despite the morose imagery her concern for her family is evident. Perhaps she was considering herself in the surviving family member’s position and would want to know what was happening. Another participant was similarly worried about her family not understanding why donation was occurring:

GD4: ‘Cause if something happens to you terminally you can’t speak for yourself so they might be shocked when the hospital’s saying, ‘OK, well we’ve gotta operate now.’ And they may just be in shell-shock like, ‘What are you doing?’

Family 5 wanted to ensure their family knew of their OD intentions so that if a family member were involved in such a situation, he or she would be able to promptly “bring it to somebody’s attention.” In other words, this family did not want to leave a surviving family member in the position of having to make a decision without prior knowledge under strict time constraints. The final instance of the subtheme peace of mind occurred in Family 7’s conversation. One participant stated that she thought it was important to discuss OD with your family so that if you don’t have a living will with your wishes defined, the surviving family members would not be left to make a blind decision.

Power and conflict. More so than the peace of mind concern, participants discussed who would be in charge of consenting for them and the power struggles that could arise. A participant in Family 1 expressed concern with being involved in the consent decision with her family after a loved one had died. She stated, “I guess coming to an agreement with all the people...that are involved in the decision. Or like who really has like who has the power to make a final decision on that...’Cause that can be a power struggle.” Similarly, a participant in Family 4 expressed her concern that conflict may arise among siblings and stated, “...I mean who has the power to make that decision in those type of situations...I guess you just don’t want anyone to argue over – I would hope nobody would argue.” She was also concerned about putting someone in charge who she could trust to make the right decision without bombarding every other person in her family. Unlike the other family who voiced this concern, Families 1 and 4 did not use a hypothetical scenario to help inform their responses.

Family 3, however, used themselves as examples. For instance, one participant expressed her strong desire to defer the consent decision to her daughter (a nurse) because she felt that her husband would be incapable of making an educated and unemotional decision. She explained his inability to deal with grief and death openly as a major obstacle to seeing that her wishes were carried out after death. In this case she was concerned about leaving her family in a position where they could not agree on a decision, so she put a well-respected family member with a medical background in charge of decision-making during life and death crises. This kind of preparation was not

evident in any other family conversations. Again, perhaps their personal experiences throughout their nursing careers have enabled them to prepare.

Hypothetical scenarios. Five of the seven families used at least one hypothetical scenario to help explain why they felt a certain way. Hypothetical scenarios involved either potential ethical dilemmas or familial situations using real family members as subjects. Each of these subthemes also emerged in the Pitts et al. (2009) study though I did not use pre-existing themes to code my transcripts. More about the similarities between this and my study are discussed further in the next chapter. The findings are presented in two sections – ethical hypothetical scenarios and family hypothetical scenarios.

Ethical hypothetical scenarios. Ethical hypothetical scenarios began with the phrases “let’s say” or “what if” and involved non-family member subjects involved in fictional situations usually related to the myths (preferential treatment or medical mistrust) or lack of knowledge about OD. A participant in Family 2 was the only participant in his family to raise any ethical hypothetical scenarios. First he presented an ethical hypothetical scenario in which an influential and wealthy senator was on the waiting list. The exchange for this first hypothetical scenario went as follows:

N2: Let’s say there’s a rich person on that waiting list who has financial influence over the hospital, and could be maybe somehow put to the top of the list. And then you come on the market but your heart’s still beating like in that video.

A2: Well that’s unethical. Doctors can’t do that!

N2: Do you – well it is unethical! So where are the check and balances?

Shortly after this exchange the nephew raised another ethical hypothetical scenario about whether or not a smoker deserved a lung transplant. Although this exchange was less passionate than before, it led to a more detailed conversation in which they used real life narratives about other family members and Mickey Mantle.

Family hypothetical scenarios. The most common type of hypothetical scenario presented involved real family members and was related to the consent process. A participant in Family 2 expressed his concern with being responsible for consenting for his sister's boyfriend in the case that they got married, her husband died, and had no surviving next-of-kin. However there is a slim chance he would ever become the next-of-kin for his sister's future husband. A participant in Family 3 also expressed his concern that his family may disagree and not respect his OD wishes. Although, because he is married, his wife would be the primary next-of-kin to consent to donation and technically his family's objections would not impact the final decision. Hypothetical scenarios such as these which involve highly unlikely circumstances may point to the lack of knowledge about the consent process. Additionally, these scenarios involve the subthemes "concern for self" and "concern for family" based on their exaggerated issues related to consenting for another and ensuring their wishes are respected.

A participant in Family 4 was also concerned with having to consent for her domestic partner. Because he is not a registered organ donor, she was hypothetically worried about whether he had not registered because he was against OD or if he had just never considered it. Her hypothetical scenario was used to justify the importance of

discussing OD with family. Although this was a hypothetical scenario, the likelihood of it actually occurring was higher than in the other families' hypothetical scenarios.

Finally participants from families 5 and 7 voiced concerns about consent if their real life circumstances were reversed. Whereas these situations would not occur because the families already knew what each family member's OD wishes were, it was worth noting that these families felt it necessary to solidify their positions as supporters of OD. For instance, a participant in Family 5 stated, "I personally have a tough situation if one of you didn't [register] and you passed away and you didn't say whether you wanted to or not." In other words she was concerned that had her parents not been registered organ donors after they died and had not discussed their wishes with her, she would find it difficult to refuse consent.

Other findings. Other interesting findings from the family conversations that did not fit any of the themes previously discussed included after-thoughts participants had following their discussion about the media portrayals. Family 1 had a brief exchange in which one participant reconsidered her OD decision.

S21: I feel like I'm rethinking my decision to be an organ donor.

S11: Really?! Are you – I thought you are one.

S21: I am an organ donor.

[1 turn omitted]

S21: I feel like I've always seen it as an act of compassion, but that might be because I've only ever seen it that way.

[1 turn omitted]

S21: I've never been like in a situation where I've experienced something like that for myself.

Obviously the intention of this study was not to discourage OD but apparently throughout this family's conversation, one participant considered the consequences of her inexperience with OD. Perhaps she felt that her decision to be a donor was not well thought out. Another participant discussed her personal registration experience after she learned about her sister's hesitation. Maybe the other participant began to doubt her own decision as a donor as well:

S11: I feel like when I made the decision to be an organ donor [pause] umm like I was getting my driver's license so it was just kind of like in the moment like, 'Do you want to be an organ donor?' like 'yes or no.' It wasn't like I hadn't like really thought of it that much I guess before...

Finally, a participant in Family 2 indirectly expressed the influence of television on her knowledge of OD. During the discussion in which another participant raised the preferential treatment myth, she attempted to put his mind at ease by explaining the OD process based on her television viewing experience:

A2: I don't know how the hospitals operate but from – and I watch a hell of a lot of TV – and from what I know from watching TV, I'm pretty sure if you're like about to expire you're – whoever is you know like the executor or the closest one there might be a do not resuscitate thing you sign. There's gonna be some form – so there's gonna be something – some protocol before anything.

Although it is unclear whether or not she watches fiction or nonfiction television mostly or to what shows she was referring, this finding exhibits the potential influence television may have over people's OD knowledge.

RQ4: What reasons do family members give for registering or not as organ donors?

I explicitly asked each family, "What are the reasons behind your decision to register (or not) as an organ donor?" Four themes emerged including the following: don't need them after death; help someone else; family influence; and never thought about it. Although I also asked each family whether or not they felt their family had an influence on their decision to register or not, the "family influence" theme emerged before I introduced this question. Thus only the responses that were received before I asked about family influence were included.

To help others. Five of the seven families responded that they want to help people after they die by donating their organs. The desire to help others was expressed in many different ways from expressing compassion for those in need of a transplant to a simple, unemotional response as evident in these three separate responses:

GD4: ...I decided to sign up because I feel like if something happens to me, somebody else in need could really, really use that.

N2: If it can be utilized for scientific purposes or actually extend somebody's life then why not right?

M5: I think my decision to register would be based on helping other people.

Furthermore, the "help" response was secondary in two of these five cases to the next most common response that organs are not needed after death.

Don't need them after death. Four of the seven families included at least one individual who stated that he or she would have no use for their organs after death. The exact phrasing was similar in all instances with the individual responding that he or she would not need them after death:

S11: Well, if I'm dead I don't see how I could need my organs at all...

A2: Can't take 'em with me when I go. I don't need 'em anymore!

In two of the families this response was shared before anyone else could respond. The tone of these responses gave the impression that the answer to the question was obvious. Furthermore, they did not seem concerned that another family member may object. In each instance no objections were expressed. Instead, family members nodded or stated that they agree and then gave another reason for registering as a donor.

Family influence. Another reason for registering as a donor was related to family influence. Although I did ask a question during the family discussions about whether or not they felt family had an influence on their decision to register or not, two families expressed family influence as their reason before I asked the question. In one of these families, the participant stated straightforward, "I registered because my mom was." The participant in the other family on the other hand attributed family influence as a reason for not registering stating, "My reasoning is because you know it was just something my parents never – I don't think they are. It was never something they brought to me."

Never thought about it. The final theme was found as a reason to not register as an organ donor. The participant who stated that his parents never discussed OD with him also stated that he had never thought about OD. Within this same family, another

participant expressed, “We [my family and I] just never thought about it.” Interestingly she also explained that at her age (over 65) she doesn’t want to discuss OD or living wills, implying that these topics bring up unpleasant thoughts about death. At the end of each of these participants’ statements they expressed that they did not think OD was bad.

Chapter Five: Discussion

Analysis of live family conversations about OD supported previous findings that people think OD is good regardless of donor status and that lack of knowledge about OD increases belief in myths. However, contrary to recent research this study revealed several novel findings. Almost all previous research about family communication and OD has been quantitative in nature or involved the use of recall data. This study's use of live family discourse had both advantages and limitations. Below I discuss the results including the implications for practice and theory, future recommendations, and limitations.

The importance of family communication about OD

All of the participants from all families agreed that family communication about OD is important though some did not believe that it was necessary. Despite these attitudes in support of family communication, several of the families mentioned the fact that aside from this study they had never previously discussed OD. This study affirms that The Gallup Organization (2005) poll findings that most families have not discussed OD still holds true today despite recent research suggesting family communication as the most important hurdle for gaining consent. Rodrigue et al. (2006) found that when the deceased's intentions were not known consent was significantly lower (26.7 percent); however, when those asked for consent knew what the deceased wanted 73.3 percent of

families consented. Consequently not knowing the deceased family member's wishes is one of the most common reasons for family disagreement which also leads to lower instances of consent (Rodrigue et al., 2008a). To break this cycle, family communication is imperative.

Family disagreement, conflict, and power struggles were commonly reported concerns during the family conversations. Participants were mostly worried about respecting their loved one's wishes when it came time to consent. Acknowledging the potential for family disagreement is perhaps a way for families to initiate OD discussions. In other words, this recognition is one way for family members to ensure that they leave their surviving family with as little responsibility as possible. In some cases OD discussions may even spark a conversation about the importance of a living will as one family did in my study.

On the other hand, not all families will disagree with one another at the time of consent. Some families found it important to talk about OD with each other so that they would not be shocked when it came time for donation. I called this subtheme "peace of mind," and it existed in both concerns for self and for family members. Family communication alleviated personal concerns by offering peace of mind that the individual's wishes would be respected now that their family knew what to do. Furthermore, family communication alleviated concerns for family members by ensuring that families would not be left in a situation where they have to consent blindly to the donation of their loved ones organs. No research to date has reported on the almost therapeutic effects of family communication about OD.

Pitts et al. (2009) analyzed 21 recordings of family communication to determine how families communicate and initiate the topic of discussion. Differences between the Pitts et al. (2009) study and my study include the method of collecting records – no researcher was present in the Pitts et al. study – and I was more interested in the content of the family discussion. However the combination of the two studies offers insights not otherwise found in current research. For example Pitts et al. (2009) found several hypothetical scenarios throughout their transcripts including those about ethical dilemmas and family situations as found in my study. Furthermore, the families in the Pitts et al. (2009) study appeared concerned about their personal well-being as well as their family members'. However unlike my study the families in the Pitts et al. (2009) study did not express concern for others such as the two families in my study who were worried about the quality of their donated organs. My participants had similar knowledge gaps and reported the same myths particularly about preferential treatment and medical mistrust. Additionally participants from both studies emphasized the importance of making the decision to become an organ donor on a personal basis.

The processes of family discussions from my study mostly followed the “collaborative” discussion style as described by Pitts et al. (2009). Participants were open and actively engaged in the conversation and often shared reasons as to why they felt the way they did about OD even when an explanation was not solicited. Also participants were not hostile, challenging, or coercive towards others. When each participant’s perspective was heard typically the conversation moved forward to the next question. Interestingly the average time of a family discussion in my study was almost seventeen

minutes just five minutes more than the average collaborative family discussion in the Pitts et al. (2009) study.

Contrary to the expected results about transportation and media effects, media interventions did not appear to influence attitudes, intentions, or the context and tone of the family conversations. Although I could not statistically measure changes in attitudes and intentions or level of transportation, comparisons of all survey data revealed little between group differences. In fact participants were not as transported as expected. However, these findings are not generalizable due to the small sample size and lack of ethnic/racial diversity.

Furthermore, OD specific media were apparently difficult for participants to recall initially. Nevertheless even when they were able to recall a television show or movie about OD, participants added that it was fiction and positive. On the other hand, Morgan et al. (2005) found that most participants recalled mostly negative portrayals of OD, though they too found it difficult to recall specific episodes or storylines. Why did participants in my study only remember OD messages to be positive when research shows how negative these messages actually are? More research into what constitutes positive and negative among television viewers may help answer this question. Most participants understood negative portrayals to mean anti-OD, but researchers consider the myths portrayed on television negative as well. Perhaps participants have heard the myths about OD so frequently and from so many sources that they cannot distinguish between what they learned from television or the information they have received from more credible sources. This is a severe disconnect that must be addressed.

Even more common than recalling OD messages in my study was the ability to recall other causes and campaigns such as Relay for Life, blood drives, or even COPD campaigns. Perhaps OD advocates could borrow strategies used by these well-known campaigns to increase awareness about OD. Recommendations such as this were also offered by many participants who seemed concerned about their own and the public's lack of knowledge about OD.

An interesting finding came from the conversation of Family 3 when compared with the conversations of all the other families and even the families in the Pitts et al. (2009) study. Family 3 consisted of two nurses and a third non-medical person with a greater than average knowledge about nursing practices. Family 3 was the only family not to mention a single myth about OD. I think this is worth noting because knowledge about OD processes has been associated with beliefs in the myths about OD (see Irving et al., 2012; Quick, Morgan, LaVoie, & Bosch, 2013).

Future Research and Practice

I have already mentioned some of the implications of this study to both theory and practice in the fields of communication and OD but would like to offer a couple more recommendations for future practices and research. First and foremost is the lack of education surrounding OD. I consider the suggestions offered by participants in my study to increase awareness justification for a stronger effort on the part of OD advocates and professionals in the health communication field. However I believe the struggle lies with whom to hold accountable for raising awareness. Considering how most non-profit organizations like Susan G. Komen Foundation and Relay for Life began as small one-

person operations, I recommend a grassroots effort to start. Based on the state of the economy, government funding for public health campaigns is likely low on the list of priorities. Furthermore, local organ procurement organizations across the country may not have the resources including time and man-power to maintain a strong community presence for OD. This recommendation refers to OD messages in practice.

OD theory specifically related to family communication simply is too limited at this point. More qualitative research is needed to gain a stronger understanding how and what families talk about when discussing OD. Live discourse is also more valuable than recalled discussions though data are more difficult to obtain. A frequent topic of discussion among communication scholars is the importance of working with scholars in other fields of research and practice. This is true too for OD communication research which is most commonly found in OD specific journals like *Clinical Transplantation* or *Progress in Transplantation* or even medical and nursing journals. If awareness is to be raised about OD then scholars and professionals from communication and medicine or nursing alike will need to work collaboratively.

Limitations

There are several limitations to this study such as the small sample size which has been discussed earlier in this paper. Another limitation to the sample aside from its size is the lack of ethnic/racial diversity. Considering that when it comes to OD the least studied and registered population of people in the United States is African Americans, this study would no doubt have benefited from the inclusion of African Americans. Unfortunately I was unable to find any interested African Americans to participate. Despite the

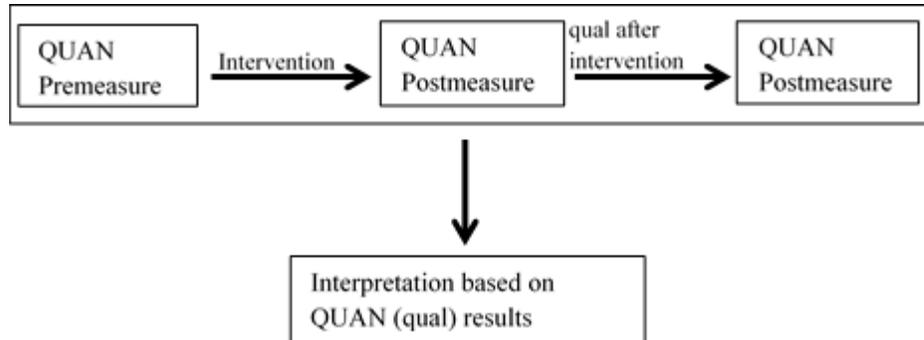
demographic diversity of the geographic area in which these interviews were conducted, my network was limited. A final limitation to the sample was that a majority of participants were female and organ donors.

Additionally I was extremely ambitious in my proposal for this study. Although ambition is a wonderful quality in some instances, it most likely clouded my ability to set realistic, attainable goals in the amount of time available. Unfortunately I was unable to statistically analyze any of the survey data. A mixed-methods study would be beneficial to the field of OD and should still be pursued.

Other limitations include the location of the study, familiarity with the intervention videos, the presence of the researcher during data collection, and participant fatigue. First, although participants were most likely more comfortable at home than in a lab setting, there tend to be several distractions at home such as non-participants walking in and out of the room or phone calls and text messages. Second, my presence as a researcher most likely inhibited some participants. Perhaps there are family issues that they would be more comfortable discussing during a private conversation. That is one of the advantages of allowing the participants to record and facilitate the discussion on their own. However, they may not know what to discuss and my questions may have enhanced the conversations. Another limitation may have been familiarity with the intervention. Participants who viewed the *Grey's Anatomy* video were familiar with the show, though they may not be regular viewers. Still, this familiarity could have been a factor in the limited transportation effects found. Finally, participant fatigue was certainly an issue. Although the study took less than an hour to complete, the surveys contained the same

measurement items for attitudes and intentions. One participant asked if I knew the questions were the same, despite having rearranged and reverse-coding some.

Appendix A: Mixed Methods Concurrent Embedded Experimental Design



Appendix B: Personal Experience Survey

INSTRUCTIONS: Please complete the following form about your personal experience with organ donation and transplantation. You may circle the Y for Yes or the N for No.

1. **Y N** I have received an organ transplant, or am on the waiting list to receive an organ.
2. **Y N** I have personally donated an organ.
3. **Y N** I am a registered organ donor.

Appendix C: Pretest

INSTRUCTIONS: Please complete the following form based on your attitudes/beliefs about organ donation by circling a number 1-5 to represent how much you agree or disagree with the statement.

SD – Strongly Disagree; SA – Strongly Agree

(SD) 1---2---3---4---5 (SA)

- | | |
|---|-------------------|
| 1. I view organ donation as a negative procedure. | 1---2---3---4---5 |
| 2. I support the idea of organ donation for transplantation purposes. | 1---2---3---4---5 |
| 3. I believe that organ donation is an unselfish act | 1---2---3---4---5 |
| 4. I view organ donation as a benefit to humanity. | 1---2---3---4---5 |
| 5. I see organ donation as a natural way to prolong life. | 1---2---3---4---5 |
| 6. I believe that organ donation is an act of compassion | 1---2---3---4---5 |

INSTRUCTIONS: Please complete the following form based on your intentions to donate by circling a number 1-7 to represent your willingness to donate.

1 = extremely unwilling; 7 = extremely willing

1--2--3--4--5--6--7

- | | |
|--|---------------------|
| 1. How willing are you to donate your own organs after death? | 1--2--3--4--5--6--7 |
| 2. How willing are you to donate the organs of a deceased loved one? | 1--2--3--4--5--6--7 |

Appendix D: Posttest Group A

INSTRUCTIONS: Please complete the following form based on your attitudes/beliefs about organ donation by circling a number 1-7 to represent how much you agree or disagree with the statement.

SD – Strongly Disagree; SA – Strongly Agree

- | | (SD) 1---2---3---4---5 (SA) |
|---|-----------------------------|
| 1. I view organ donation as a negative procedure. | 1---2---3---4---5 |
| 2. I support the idea of organ donation for transplantation purposes. | 1---2---3---4---5 |
| 3. I believe that organ donation is an unselfish act | 1---2---3---4---5 |
| 4. I view organ donation as a benefit to humanity. | 1---2---3---4---5 |
| 5. I see organ donation as a natural way to prolong life. | 1---2---3---4---5 |
| 6. I believe that organ donation is an act of compassion | 1---2---3---4---5 |

INSTRUCTIONS: Please complete the following form based on your intentions to donate by circling a number 1-7 to represent your willingness to donate.

1 = extremely unwilling; 7 = extremely willing

- | | 1---2---3---4---5---6---7 |
|--|---------------------------|
| 1. How willing are you to donate your own organs after death? | 1---2---3---4---5---6---7 |
| 2. How willing are you to donate the organs of a deceased loved one? | 1---2---3---4---5---6---7 |

INSTRUCTIONS: Please complete the following form by circling a number 1-7 to represent how much you were doing the stated action from Not at all to Very Much.

**(Not at all) 1---2---3---4---5---6---7
(Very Much)**

- | | |
|--|---------------------------|
| 1. While I was watching the episode, activity going on in the room around me was on my mind. | 1---2---3---4---5---6---7 |
| 2. I could picture myself in the episode as it was playing. | 1---2---3---4---5---6---7 |
| 3. I was mentally involved in the episode while watching it. | 1---2---3---4---5---6---7 |
| 4. After watching the episode, I found it | 1---2---3---4---5---6---7 |

- easy to put it out of my mind.
5. I wanted to learn how the narrative ended. 1----2----3----4----5----6----7
 6. The episode affected me emotionally. 1----2----3----4----5----6----7
 7. I found myself thinking of ways the episode could have turned out differently. 1----2----3----4----5----6----7
 8. I found my mind wandering while watching the episode. 1----2----3----4----5----6----7
 9. The events in the episode are relevant to my everyday life. 1----2----3----4----5----6----7
 10. The events in the episode have changed my life. 1----2----3----4----5----6----7

INSTRUCTIONS: Please complete the following form based on your ratings of the character described by circling a number 1-7 to represent how much you believe that character is described by the adjective. The closer a number is to one of the adjectives, the more you believe the character is that way.

1. Rate the following characters:

a.	Dr. Miranda Bailey (leader of domino surgery)							
Bad	1	2	3	4	5	6	7	Good
Irresponsible	1	2	3	4	5	6	7	Responsible
Pleasant	1	2	3	4	5	6	7	Unpleasant
Unattractive	1	2	3	4	5	6	7	Attractive
b.	Mistress (donor 1)							
Bad	1	2	3	4	5	6	7	Good
Irresponsible	1	2	3	4	5	6	7	Responsible
Pleasant	1	2	3	4	5	6	7	Unpleasant
Unattractive	1	2	3	4	5	6	7	Attractive
c.	Wife (donor 2)							
Bad	1	2	3	4	5	6	7	Good
Irresponsible	1	2	3	4	5	6	7	Responsible
Pleasant	1	2	3	4	5	6	7	Unpleasant
Unattractive	1	2	3	4	5	6	7	Attractive

Appendix E: Posttest Group B

INSTRUCTIONS: Please complete the following form based on your attitudes/beliefs about organ donation by circling a number 1-7 to represent how much you agree or disagree with the statement.

SD – Strongly Disagree; SA – Strongly Agree

- | | (SD) 1---2---3---4---5 (SA) |
|---|-----------------------------|
| 1. I view organ donation as a negative procedure. | 1---2---3---4---5 |
| 2. I support the idea of organ donation for transplantation purposes. | 1---2---3---4---5 |
| 3. I believe that organ donation is an unselfish act | 1---2---3---4---5 |
| 4. I view organ donation as a benefit to humanity. | 1---2---3---4---5 |
| 5. I see organ donation as a natural way to prolong life. | 1---2---3---4---5 |
| 6. I believe that organ donation is an act of compassion | 1---2---3---4---5 |

INSTRUCTIONS: Please complete the following form based on your intentions to donate by circling a number 1-7 to represent your willingness to donate.

1 = extremely unwilling; 7 = extremely willing

- | | 1---2---3---4---5---6---7 |
|--|---------------------------|
| 1. How willing are you to donate your own organs after death? | 1---2---3---4---5---6---7 |
| 2. How willing are you to donate the organs of a deceased loved one? | 1---2---3---4---5---6---7 |

INSTRUCTIONS: Please complete the following form by circling a number 1-7 to represent how much you were doing the stated action from Not at all to Very Much.

**(Not at all) 1---2---3---4---5---6---7
(Very Much)**

- | | |
|--|---------------------------|
| 1. While I was watching the episode, activity going on in the room around me was on my mind. | 1---2---3---4---5---6---7 |
| 2. I could picture myself in the episode as it was playing. | 1---2---3---4---5---6---7 |
| 3. I was mentally involved in the episode while watching it. | 1---2---3---4---5---6---7 |
| 4. After watching the episode, I found it | 1---2---3---4---5---6---7 |

- easy to put it out of my mind.
5. I wanted to learn how the narrative ended. 1---2---3---4---5---6---7
 6. The episode affected me emotionally. 1---2---3---4---5---6---7
 7. I found myself thinking of ways the episode could have turned out differently. 1---2---3---4---5---6---7
 8. I found my mind wandering while watching the episode. 1---2---3---4---5---6---7
 9. The events in the episode are relevant to my everyday life. 1---2---3---4---5---6---7
 10. The events in the episode have changed my life. 1---2---3---4---5---6---7

INSTRUCTIONS: Please complete the following form based on your ratings of the character described by circling a number 1-7 to represent how much you believe that character is described by the adjective. The closer a number is to one of the adjectives, the more you believe the character is that way.

1. Rate the following characters:

a.	Carolyn Henry-Glaspy (mother of donor)							
Bad	1	2	3	4	5	6	7	Good
Irresponsible	1	2	3	4	5	6	7	Responsible
Pleasant	1	2	3	4	5	6	7	Unpleasant
Unattractive	1	2	3	4	5	6	7	Attractive
b.	Brian Polk (kidney recipient)							
Bad	1	2	3	4	5	6	7	Good
Irresponsible	1	2	3	4	5	6	7	Responsible
Pleasant	1	2	3	4	5	6	7	Unpleasant
Unattractive	1	2	3	4	5	6	7	Attractive
c.	Dr. John Green (donor's trauma surgeon)							
Bad	1	2	3	4	5	6	7	Good
Irresponsible	1	2	3	4	5	6	7	Responsible
Pleasant	1	2	3	4	5	6	7	Unpleasant
Unattractive	1	2	3	4	5	6	7	Attractive

Appendix F: Posttest All Groups

INSTRUCTIONS: Please complete the following form based on your attitudes/beliefs about organ donation by circling a number 1-7 to represent how much you agree or disagree with the statement.

SD – Strongly Disagree; SA – Strongly Agree

- | | (SD) 1---2---3---4---5 (SA) |
|---|-----------------------------|
| 1. I view organ donation as a negative procedure. | 1---2---3---4---5 |
| 2. I support the idea of organ donation for transplantation purposes. | 1---2---3---4---5 |
| 3. I believe that organ donation is an unselfish act | 1---2---3---4---5 |
| 4. I view organ donation as a benefit to humanity. | 1---2---3---4---5 |
| 5. I see organ donation as a natural way to prolong life. | 1---2---3---4---5 |
| 6. I believe that organ donation is an act of compassion | 1---2---3---4---5 |

INSTRUCTIONS: Please complete the following form based on your intentions to donate by circling a number 1-7 to represent your willingness to donate.

1 = extremely unwilling; 7 = extremely willing

- | | 1----2----3----4----5----6----7 |
|--|---------------------------------|
| 1. How willing are you to donate your own organs after death? | 1----2----3----4----5----6----7 |
| 2. How willing are you to donate the organs of a deceased loved one? | 1----2----3----4----5----6----7 |

Appendix G: Family Discussion Questions

- 1) What are the reasons behind your decision to register (or not) as an organ donor?
- 2) Does your family play a role in your decision to register (or not) as an organ donor?
- 3) Do you feel you should tell your family if you decide to register (or not) as an organ donor?
- 4) What are some issues that come to mind when you think about donating your own organs, or consenting to donating the organs of a relative or loved one?
- 5) What have you seen, heard, or read in the media about organ donation?

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Curriculum Vitae

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