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Understanding the Public's Attitudes Toward Tissue Donation: A Multi-Method Approach

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor
of Philosophy at Virginia Commonwealth University

by

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I dedicate this dissertation to my best friend and soon-to-be husband,
Benjamin Saul, for standing by me every step of the way. I love you.

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Abstract

UNDERSTANDING THE PUBLIC'S ATTITUDES TOWARD TISSUE DONATION: A MULTI-METHOD APPROACH

Lindsey A. Kurland

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

Virginia Commonwealth University, 2013

Major Director: Laura A. Siminoff, Professor and Chair, Department of Social and Behavioral Health

The impact of deceased tissue donation and transplantation is far-reaching; however, little is known about the public's attitudes towards tissue donation. Siminoff, Traino, and Gordon (2010) found that families' attitudes towards tissue donation were a significant predictor of consent; specifically, families that were initially favorable towards tissue donation were more likely to donate their loved ones tissues than families that were initially unfavorable towards tissue donation. Using a qualitative coding approach and the Tripartite Model of Attitude Structure (affective, behavioral, and cognitive attitude components) as a conceptual framework, families' expressed attitudes toward tissue donation were extracted from $N=240$ audiorecordings of past tissue donation requests from 16 different OPOs. In addition, semi-structured interviews were conducted with $N=14$ Tissue Requesters from LifeNet Health in Virginia Beach, Virginia about their perceptions of families' attitudes. Together, 14 attitude domains and 34 subdomains were

derived from the families' expressed attitudes. Several multivariate analyses were performed. After controlling for time spent discussing tissue donation and confusion between tissues and organs, affective attitudes were significantly different among three FDM initial response groups (favorable, unsure, and unfavorable). Further, the attitude domains "donation invokes positive emotion" and "pro-donation behaviors" were the best discriminators of FDM groups. Suggestions for educational interventions were discussed.

Keywords: deceased tissue donation, attitudes, tissue requesters, Tripartite Model of Attitude Structure

Chapter I. Introduction

Tissue donation affects over one million American lives every year (American Academy of Tissue Banks [AATB], 2010). Donated tissues, such as skin and heart valves, are used in life-saving capacities. For example, donated skin can be used to prevent dehydration for burn victims and heart valves may be used to restore function to defective valves (Musculoskeletal Transplant Foundation [MTF], 2005). Similar to solid organ donation, the success of tissue donation is contingent on individuals' consent to donate their tissues and families' consent to donate their loved ones' tissues. Yet consent rates for tissue donation remain low (Siminoff, Traino, & Gordon, 2010). In a national study of 238 families of eligible deceased patients who were approached by health care professionals requesting tissue donation, Siminoff, Arnold, Caplan, Virnig, and Seltzer (1995) found that only 35% of families consented. Because there are relatively large numbers of potential donors, even raising the rates of donation by a modest amount would yield a significant number of new donors. For example, Rodrigue, Scott, and Oppenheim (2003) estimated that increasing the consent rate by 10% would increase the pool of transplantable tissues by 100,000 grafts. However, increasing the consent rate for tissue donation is a challenging task as it is so poorly understood by the public and is often confused with solid organ donation. In a survey of families who donated tissues, only one-half distinguished tissue donation from organ donation (Wilson et al., 2006). This should not be too surprising considering the attention organ donation has received in the media and through educational campaigns, compared to the lack of similar efforts regarding tissue donation.

Public attitudes regarding tissue donation shape tissue donation decisions (Beard, Ireland, Davis, & Barr, 2002; Rodrigue, Scott, & Oppenheim, 2003; Siminoff, Traino, & Gordon, 2010). Yet, the amount of research on attitudes toward tissue donation is scant compared to that on organ donation. Previous studies examining tissue donation have narrowly explored these issues, being limited by structured survey questionnaires that have been adapted from studies on organ donation and retrospective samples of families who consented to donation. The few studies that do exist have shown that families with unfavorable attitudes toward donation are significantly less likely to donate tissues than families with favorable attitudes (Rodrigue, Scott, & Oppenheim; Siminoff, Traino, & Gordon). Furthermore, families know little about tissue donation, confuse tissue and organ donation, and are surprised to receive requests for tissue donation at the time of their loved one's death.

Chapter II. Literature Review

Despite the overwhelming attention of clinicians, the media and politicians on organ transplantation, tissue transplantation occurs on an even larger scale (Price, 2010, p.10). Arguably, tissue donation is equally as 'life-saving' as some forms of organ transplantation (Price). Each year, approximately 30,000 individuals donate tissue. Moreover, tissue from just one individual donor can be distributed to and help over 50 people (Donate Life America, 2012). This review will focus on three areas important to understanding attitudes toward tissue donation: 1) types of donated tissue and its uses, 2) family decision-makers and consent for tissue donation, and 3) persuasive and relational communication. The first area will highlight the need for and impact of tissue donation on individuals and society. The second area introduces two groups of individuals (family decision-makers and tissue requesters) that are perhaps most integral to making the donation of deceased tissue possible. It is thus important to understand their roles and perspectives in tissue donation, due to their firsthand experience with the process. A description of the tissue donation consent process in the second section provides details about the timing and sequence of events. This brings us to the third area of discussion. Specifically, the third area describes persuasive and relational communication, a significant external factor influencing families' attitudes during requests that has been recently examined by Siminoff, Traino, and Gordon (2011).

Types of Donated Tissue and Its Uses

First, it is important to be acquainted with a definition of deceased tissue donation, the types of tissue that can be donated and their uses. Deceased tissue donation is inclusive of corneas, tendons, ligaments, veins, skin, heart valves, bone and other associated tissue (Donate Life America, 2012). Donated tissue may be used for many different purposes including, transplantation, medical research, and education.

Transplantation. Transplantation is an accepted medical practice for a rising number of conditions. Some examples of transplanted tissues and their uses are provided below.

Eyes. Corneal transplantation, the most frequently performed transplant procedure, restores sight to the blind (Donate Life America, 2012; Southeast Tissue Alliance [SETA], 2009b). Several thousand Americans remain on waitlists every month to receive corneas. The white part of the eye, known as the sclera, is another commonly sought after tissue as it is used as patch grafts for patients with glaucoma. The sclera can also be used as oral grafts in dental procedures (SETA).

Bone. Donated bone from multiple sites in the human skeleton can be used to support bone structure for conditions such as trauma, infection, metabolic disorders, and cancer (SETA, 2009b). Specifically, long bones, such as the femur and tibia, can be used for limb salvage procedures, especially in younger patients with cancer. Bone tissue may also be processed into different forms that often do not resemble the original tissue. Examples include screws, dowels, and bone chips which may be used to secure or stabilize other transplanted tissues. Powdered bone is commonly used to secure dental implants (MTF, 2005).

Cartilage. Cartilage is often used to repair defects in joints from trauma, vascular causes, and other idiopathic causes of focal bone loss (SETA, 2009a). It may also be used for cosmetic procedures such as eyelid repair and facial disfigurement.

Tendons and ligaments. Tendons (e.g. from rotator cuffs, the Achilles, hamstrings, quadriceps, the hand, and forearm) are used to restore function to the shoulder, wrist and hand, ankle, knee, and elbow (SETA, 2009a). Donated ligaments can be used to restore function and mobility in the knee and other joints (SETA, 2009b).

Veins. Every year, several thousand vascular transplants are possible with the donation of veins (Coalition on Donation & MTF, 2004). For example, patients suffering with arterial insufficiency, often those with diabetes, can avoid limb amputation with surgery that uses a donated vein to re-establish blood circulation. Donated veins, such as saphenous and femoral veins of the lower extremity and from the internal mammaries, are used to perform bypass procedures of the heart.

Heart valves. Donated heart valves, which direct the flow of blood between the chambers of the heart, can be transplanted into patients with heart disease and deformities (SETA, 2009b). Children with leaky and defective heart valves who receive donated heart valves can subsequently experience an increase in energy and have a prolonged life. Half of donated heart valves are transplanted into children under the age of 15 (SETA).

Pericardium. Donated pericardium, the protective lining around the heart, can be used for Dura Mater replacement in patients needing brain surgery (SETA, 2009a).

Skin. Donated skin may be used as grafts for patients with loss of skin from severe burns or trauma and for patients needing reimplanted limbs or digits (e.g., fingers, toes) (MTF, 2005; SETA, 2009a). These grafts serve to relieve pain and restore normal

physiology. Moreover, donated skin may be used for other purposes such as cosmetic (e.g., penile enlargement, smoothing wrinkles) or reconstructive (e.g., bladder support, breast reconstruction, eyelid repair) procedures on the face or the body.

Depending on the agency procuring the tissue, other types of tissues may be donated for a variety of additional transplant uses. The ones mentioned above are simply those that are most commonly requested and donated (SETA 2009a; 2009b). Families are often asked to donate their family member's tissues for research and/or education if the tissues are not suitable for transplantation.

Research. Researchers across the U.S. need donated tissues to study a wide array of diseases such as Alzheimer's, Cystic Fibrosis, heart disease, cancer, asthma, arthritis, liver disease, and kidney disease, to name a few. The donated tissues mentioned for transplantation can also be used for a variety of other research purposes, such as for the study of genes that are linked to certain diseases or for developing and testing pharmaceutical drugs. Both normal and diseased donated tissues are used to advance research on diagnoses, therapies and cures (National Disease Research Interchange [NDRI], 2011). Families may also donate tissues to a biobank, a repository of many different types of donated tissues for multiple researchers to use and conduct many different types of research.

Education. Finally, donated tissue may be used for educational purposes in order to advance scientific and medical knowledge. For example, ligaments and cartilage donated for education provides orthopedic surgeons with a safe way to practice newly acquired surgical techniques before operating on living patients (SETA, 2009). Donated tissue can be used in medical schools to teach students about different aspects of the

human anatomy. For example, donated brain tissue can be examined or dissected to learn about various neurological and psychological disorders.

Whether for use in transplantation, research, or education, donated deceased tissues all rely on the consent of families.

Family Decision-Makers and Consent for Tissue Donation

Also important in providing context for understanding people's attitudes toward tissue donation is a review of the consent process. Family decision-makers (FDMs) are quite often required to make decisions concerning the donation of a deceased family member's tissues. There are two main reasons for this.

First, most deceased individuals have not documented their wishes, either for or against donation, concerning tissue donation (Siminoff, Traino, & Gordon, 2010). Therefore, tissue requesters (TRs) (trained professionals hired by an Organ Procurement Organization (OPO) or other contracted third-party to request tissue donation) must approach the legal next-of-kin, most often family members, in order to obtain consent for donation. Second, although first person consent statutes have been implemented in most states, recognizing individuals' registration of their wishes on their drivers' licenses or online registries as full legal consent upon the donors' death, tissue requesters still, in practice, ask families for their permission to go ahead with patients' wishes, regardless of donor designation (DHHS-OIG, 2001). This practice continues because it is recognized that most individuals who designate themselves as donors are not aware of tissue donation *per se*.

While there are some similarities between the consent process for organ donation and that for tissue donation, one similarity being that both OPOs and tissue banks are

involved in approaching families to request consent for donation, there are many notable differences. For example, whereas families who are approached about organ donation are contacted in person by OPO Coordinators, families who are approached about tissue donation are primarily contacted by telephone by Tissue Requesters (TRs). Beard and colleagues (2002) estimated that 95% of requests for tissue donation take place over the telephone. Furthermore, families approached for organ donation usually have several face-to-face interactions with an OPO Coordinator, giving the Coordinator and family a chance to build rapport. In addition, families sometimes have a couple of days to think about organ donation and come to a decision while their loved one is receiving life supports.

Although there is more time to retrieve tissues after death as compared to organs (up to 48 hours), FDMs generally experience the decision making process as a single encounter over the telephone (Gain et al., 2002; Geissler, Gerbeaux, Maitrejean, & Durand-Gasselin, 2005; Rodrigue, Scott, & Oppenheim, 2003; Siminoff, Traino, & Gordon, 2010; 2011). Families approached for tissue donation often report some degree of surprise at receiving a telephone call from a TR who they have never met. Not only is it likely that families have received no warning about a telephone call from a TR, but studies have shown that families are often very surprised by the request for the tissue donation (e.g., Siminoff, Traino, & Gordon, 2010). Siminoff, Traino, and Gordon (2010) suggest that this element of surprise is due to the public's lack of awareness and misconceptions about tissue donation and the sensitive time at which requests are made. Moreover, due to the nature of the approach for tissue donation (through the telephone), TRs are unable to provide families with written material.

Tissues are also regulated and handled differently than organs. Whereas organs are procured and transplanted into a recipient in the shortest amount of time possible (approximately five hours or less depending on the time it takes to transport an organ to a recipient), donated tissues are usually stored, sometimes for years, at a tissue bank where they undergo sterilization and testing for infection and disease (AATB, 2010). The Food and Drug Administration (FDA) oversees the regulation of tissue banks. It mandates that medical/social history questionnaires, with questions related to sexual activity, drug use, and risky behaviors, be completed with donor families in order for a patient's tissue to be donated (AATB). Families of organ donors, on the other hand, can still donate even if they refuse to complete a medical/social history, although the organs will be labeled "high risk". Thus, the family's active cooperation is critical to the tissue donation and transplantation process.

Professional organizations such as the American Association of Tissue Banks (AATB), the Association of Organ Procurement Organizations (AOPOs), and the Eye Bank Association of America (EBAA) have attempted to standardize the consent process by issuing a statement that addresses elements of informed consent. However, federal laws do not regulate how tissue banks obtain consent (DHHS-OIG, 2001), which leads to unstandardized ways in which families are approached. This could result in some important information being given to some families and not others. Examples of discretionary information are: the tissue may be donated to for-profit companies; may be marketed and sold as medical supplies rather than a donation; and may be processed into products that are used for non-medically indicated cosmetic purposes (DHHS-OIG).

Relational and Persuasive Communication During Tissue Donation Request

In addition to the many factors mentioned above, there is also evidence that relational and persuasive communication affect a family's attitudes and decision regarding tissue donation. For example, it has been found that empathy, rapport, and sensitivity during times of high stress, anxiety and grief for families impacts the decisions families make at the time of the request (Haddow, 2004; Pelletier, 1992). In their study on heart valve donation, Haire and Hinchliff (1996) attributed success in obtaining consent to the communication and skills of the requesters who demonstrated sensitivity and experience. Similarly, Geissler, Gerbeaux, Maitrejean, and Durand-Gasselin (2005) made a compelling case for the impact that well-trained and experienced requesters can have on cornea donation consent rates. Over the course of 22 months and 100 telephone contacts, two requesters progressed from a 30% acceptance rate to over 70% after receiving ongoing training on cornea donation and grafting.

Most recently, Siminoff, Traino, & Gordon (2011) investigated the relational communication component of the request conversation (AHRQ Grant #: R01 HS-13152). Their research found that FDMs respond positively to TRs who exhibit supportive and comforting communicative behaviors during requests. Specifically, an analysis ($N=1,016$) of audiotaped requests for tissue donation found that when confirmational messages (e.g., messages that expressed validation or acceptance) or persuasive tactics, such as credibility, altruism, or esteem, were used during donation discussions, families were more likely to consent to tissue donation. Although the study demonstrated the effectiveness of TRs' specific communication practices on tissue donation behaviors (e.g., foot-in-the door, appeals to credibility, and altruistic nature of donation), a regression analysis yielded

mixed results regarding the association between the sum total use of persuasive communication in requests and consent (Siminoff, Traino, & Gordon). Furthermore, appeals to reason (i.e., the persuasive argument) and refutation of misinformation about tissue donation (i.e., countering the belief of being too old to donate) were not associated with family consent. This finding suggests that while persuasive communication may influence families' decisions to donate tissue, families are basing their decisions to consent to or refuse tissue donation on other beliefs. FDMs with favorable attitudes toward tissue donation were 3.47 times more likely to consent to donation than FDMs with unfavorable tissue donation attitudes. On the other hand, request discussions where TRs utilized persuasive communication were 1.66 times more likely to result in consent to donation than discussions where TRs did not include persuasive communication. Thus, attitudes appear to contribute more to the decision of consenting to tissue donation than the use of persuasive communication, meriting further investigation into the field of FDMs' attitudes toward tissue donation.

II. Attitudes Toward Tissue Donation

While relational and persuasive communication as well as the approach and practice of obtaining consent may influence the ultimate decision families make with regard to tissue donation, there is reason to believe that families' attitudes play as important or more important a role in the donation decision. With a sample size of over 1,000 FDMs, Siminoff, Traino, & Gordon (2010) showed that FDMs who were initially favorable toward tissue donation were significantly more likely to consent to donation. FDMs who were initially unsure about tissue donation were almost equally likely to

consent or refuse donation while FDMs who were initially unfavorable toward tissue donation were significantly more likely to refuse donation. Rodrigue, Scott, and Oppenheim (2003) found similar results. In their study, most tissue donor families (81.9%) reported that they were initially favorable to the request for tissue donation; whereas, few non-donor families (19.8%) reported such attitudes. Despite efforts by TRs to dispel myths or otherwise persuade families to donate tissue, it appears that a family's decision to consent or refuse donation may have been made long before being asked to donate their loved one's tissues.

Some studies suggest that attitudes toward tissue donation show similar trends as attitudes toward organ donation (e.g., DeJong et al, 1998; Siminoff, Gordon, Hewlett, & Arnold, 2001; Siminoff, Traino, & Gordon, 2010). For example, surveys taken of health care providers ($N=1,207$) who requested donation from families demonstrated that the best and strongest predictor of donation decisions was families' initial reaction to the donation request, predicting 91.5% of the final donation decision (Siminoff, Arnold, & Hewlett, 2001). Organ and tissue donation (OTD) researchers have thus frequently studied FDMs' attitudes in terms of three initial response groups- 1) those who were initially favorable toward donation, 2) those who were initially unsure about donation, and 3) those who were initially unfavorable toward donation- and have measured their association with consent to donation (DeJong et al; Rodrigue, Scott, & Oppenheim, 2003; Siminoff, Arnold, and Hewlett; Siminoff, Traino, & Gordon). The consistent and strong association between the initial reaction to the request and donation behavior suggests that the family's initial reaction to the request can be conceptualized as a proxy to donation behavior.

While knowledge of a family's initial reaction to a request is telling in terms of their donation decision, it is not always clear how this attitude is formed. For example, it is difficult to determine whether a family's attitude toward a request for tissue donation is specifically toward tissue donation. OTD researchers often do not explicitly distinguish attitudes towards tissue donation and attitudes toward organ donation. Several studies have assessed attitudes toward organ donation by measuring the attitudes toward donating both tissues (e.g., bone, heart valves, skin) and organs (e.g., heart, liver, kidneys); whereas, other studies have measured attitudes toward donating only one or the other (Rodrigue, Cornell, Krouse, & Howard, 2010; Siminoff, Traino, & Gordon, 2010, 2011; Prottas, 1983). Perhaps due to variability in the measurement strategies of attitudes across studies, differentiating attitudes specifically toward tissue donation and attitudes toward organ donation presents a challenge.

In order to understand how families' initial reactions or attitudes toward the request for tissue donation are formed, a theoretical framework on attitude formation will be described in the next section. This framework will be applied to the context of tissue donation and ultimately inform a strategy for the study of FDMs' attitudes toward tissue donation. Afterwards, a review of the literature on what the public's attitudes toward tissue donation are, where these attitudes come from, and when they are formed will be discussed. A few studies from the OTD literature will be cited as they lay the foundation for work done in the small field of attitudes toward tissue donation.

To recap, the next section will review: 1) the definition of attitudes, 2) how attitudes are formed including theory on attitude formation and how the theory applies to

tissue donation attitudes, 3) what the public's attitudes are toward tissue donation, 4) where these attitudes come from, and 5) when they are formed.

Definition of Attitudes

In order to understand how attitudes are formed, it is important to be familiar with a working definition of attitudes. Definitions of the attitude construct have varied over the years and across many disciplines, ranging from a "mental and neural state of readiness, organized through experience, exerting a directive or dynamic influence upon the individual's response to all objects and situations with which it is related" (Allport, 1935, p. 810) to "a relatively enduring organization of beliefs about an object or situation predisposing one to respond in some referential manner" (Rokeach, 1967, p. 530). Yet, the general consensus in the scientific community is that an attitude, in its most general form, is an evaluation (e.g., positive or negative) of a given object (Abelson & Prentice, 1989; Ajzen, 2001; Eagly & Chaiken, 1993; Fazio, 1989). More specifically, the definition of an attitude to be used here is "an association in memory between an attitude object (in this case, tissue donation) and the evaluation of a number of related acts or responses" (DeFleur & Westie, 1963; Fazio, 1990).

How Attitudes are Formed

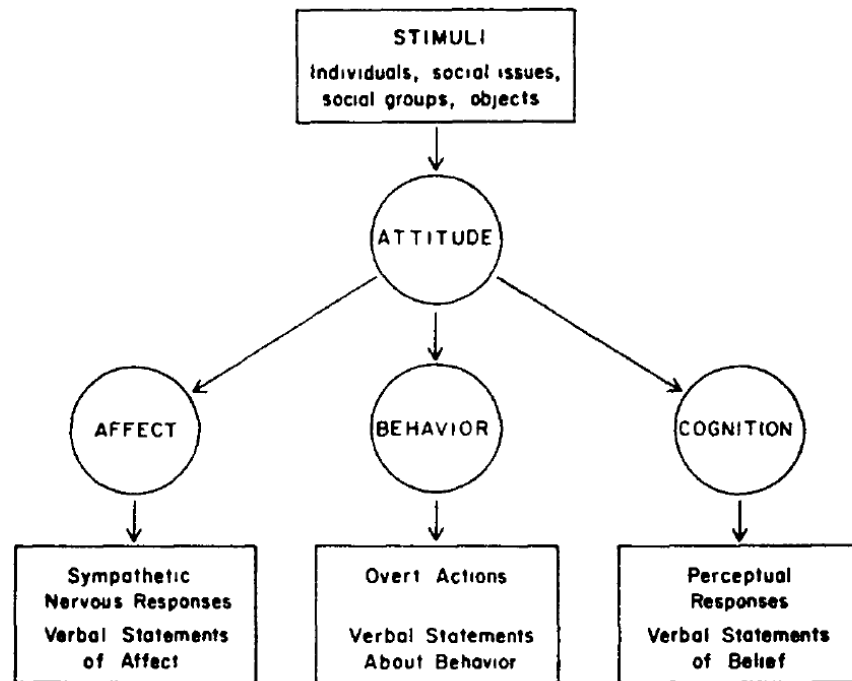
The theoretical question of exactly how attitudes are formed continues to challenge researchers across disciplines. Researchers have proposed a number of complicated models and theories to delineate the underlying mechanisms of attitudes, but few, if any, have become widely accepted or have been frequently employed in other studies. There is one model, however, dating back to the 1960's, that has been and continues to be used as

the basis for conceptualizing attitude formation, especially in the social psychology field. This model, known as the Tripartite Model of Attitude Structure (Rosenberg & Hovland, 1960), will be discussed below and will be this study's theoretical framework to explore tissue donation attitudes.

Conceptual framework. As mentioned above, an attitude can be defined as an “association in memory between an attitude object and a summary evaluation of its attributes (ie. acts or responses)” (DeFleur & Westie, 1963; Fazio, 1990). Fazio (1990; 1995) explained that the strength of this association can vary. The attributes associated with the attitude object are evaluated along a positive or negative continuum, such that people who evaluate an attitude object favorably are likely to associate it with positive attributes and unlikely to associate it with negative attributes. Similarly, people who evaluate an attitude object unfavorably are likely to associate it with negative attributes and unlikely to associate it with positive attributes (Eagly & Chaiken, 1993). Breckler (1984) stated that an attitude is also “a response to an antecedent stimulus or object” (p. 1191). Breckler also suggested that the stimulus may be seen or unseen, and can be best conceptualized as an independent variable. Furthermore, attitudes may manifest themselves as three classes of responses to that stimulus or attitude object. These classes of responses, which may be referred to as the components of attitudes, are: 1) affect, 2) behavior, and 3) cognition. Figure 1 below shows the Tripartite Model of Attitude Structure with the three components being observed in the form of verbal statements.

Figure 1

The Tripartite Model of Attitude Structure (Rosenberg & Hovland, 1960)



Note. Figure from Breckler, 1984

Breckler (1984) defined affect as “an emotional response, a gut reaction, or sympathetic nervous activity” (p. 1191). An affective attitude component can also be defined by feelings or emotions that people have in relation to an attitude object (Eagly & Chaiken, 1993). People who have positive affect reactions to a related experience or situation are more likely to evaluate an attitude object favorably. On the other hand, people are unlikely to evaluate the attitude object favorably from negative affect reactions. The classical conditioning model of attitude change was developed under the assumption that attitudes are formed via an affective mechanism (Staats & Staats, 1958). From this perspective, an attitude is a product of the pairing of an attitude object (conditioned stimulus) with a stimulus that elicits an affective response (unconditioned stimulus). As a result of repeated association, the attitude object triggers the affective response, and an

attitude is thereby formed. For example, stimuli repeatedly associated with the onset of electric shock would acquire negative evaluation via this affective process, and stimuli paired with the offset of electric shock would acquire positive evaluation (e.g. Zanna, Kiesler, & Pilkonis, 1970). Zajonc (1980) argued that attitude “preferences” (i.e., evaluations) are based primarily on affective responses, which are often immediate and are not mediated by thinking about the attributes of attitude objects. Breckler suggested other ways of measuring affect: physiological response (e.g. heart rate or galvanic skin response) or verbal reports of feelings or mood.

Behavior includes “overt actions, behavioral intentions, and verbal statements regarding behavior” (Breckler, 1984, p.1191). In other words, the behavioral component of attitudes refers to behaviors or action statements about the attitude object (Eagly & Chaiken 1993). Bem (1971) and others (Eagly & Chaiken, 1993) explained that attitudes can be derived from past behavior and can be based on either direct or indirect experiences. A self-perception account of attitude formation suggests that people tend to infer attitudes that are consistent with prior behaviors. In addition, learning theorists have described behavioral attitudes as deriving from behavioral responses. Behavioral responses also can be regarded as encompassing intentions to act that are not necessarily expressed in overt behavior (Eagly & Chaiken). In the stimulus-response behavior theory tradition, when overt behaviors (or covert cognitive responses) elicited by attitude objects are rewarded or punished, self-evaluation occurs (Hovland, Janis, & Kelley, 1953). According to many researchers, involvement is viewed as a core concept in explaining individuals’ participation in activities and their action with respect to the attitude object.

Additionally, personal relevance is thought to be an important motivational factor associated with eliciting the behavioral component of attitudes (Dillard, 2002).

Cognition includes “beliefs, knowledge structures, perceptual responses, and thoughts” (Breckler, 1984, p. 1191). The cognitive attitude component may also be based on opinions, information, and inferences (Eagly & Chaiken, 1993). Cognitive responses to an attitude object may include covert responses that occur when the associations between the attitude object and its attributes are inferred or perceived. They may also be manifested by overt responses of verbally stating one’s beliefs. The cognitive component of attitudes may be formed when an individual processes information more deeply about an attitude object (Eagly & Chaiken). However, an attitude that is encoded as a cognitive component can also be acquired more peripherally, based on a speaker’s credibility or the attractiveness of an advertisement promoting the attitude object, which may lead to false beliefs. The cognitive component of a person’s attitudes is, thus, often comprised of stereotypes or generalizations about a group of people or attitude objects in which individual differences are ignored (Bodenhausen & Lichtenstein, 1987). Stereotyping compartmentalizes the world, maximizing one’s cognitive time and energy (also known as a “representative heuristic”, which will be described later). Once stereotypes are formed, they are resistant to change in the face of new information. The assumption is that these attitudes are formed by a process of cognitive-based learning.

The cognitive component of attitudes is perhaps the most commonly measured attitude component in social and behavioral health research. Moreover, social and behavioral health theories typically default to attitudes being conceptualized as mostly or purely cognitively based, perhaps because it is the easiest component to measure. For

example, attitudes have commonly been measured in accordance with the expectancy-value model, whereby attitudes are a factorial function of its attributes, or beliefs and values (Fishbein & Ajzen, 1975). Using this model, attitudes are measured by assigning a positive or negative value to each of its attributes or beliefs. The product of the attributes equals the attitude valence, or the inherent degree of favorability or unfavorability, toward the attitude object.

There are a few assumptions regarding the attitude components. One assumption is that they all vary along a common evaluative continuum (Allport, 1935). For example, affect can vary from happy to unhappy. Behavior can range from favorable (e.g., signing or stating that you signed a donor card) to unfavorable (e.g., intentionally not signing a donor card). Cognitions may also range from favorable to unfavorable, but is more thought-based (e.g., statements that indicate support of tissue donation vs. statements that indicate opposition). Another assumption, based on theoretical underpinnings, is that the components are distinguishable in terms of how they are formed (Breckler, 1984; Triandis, 1971). For instance, attitudinal affect may not have verbal or cognitive antecedents. Similarly, the behavior component may be established through non-cognitive mechanisms (Breckler, 1984). Affect, behavior, and cognition can sometimes be generated from very different learning mechanisms (Greenwald, 1968). Moreover, even if an attitude is produced by the same learning mechanisms, the three components may be “coded” differently, implying that they can operate in partial, or even complete, independence (Zajonc, 1980).

Breckler (1984) clearly outlined five requirements for a strong test of the tripartite model, developed from general principles of construct validation (Cronbach & Meehl, 1955) and the tripartite model's theoretical basis. These are:

1. Both verbal and nonverbal measures of affect and behavior are required.
2. Dependent measures of affect, behavior, and cognition must take the form of responses to an attitude object.
3. Multiple, independent measurements of affect, behavior, and cognition are needed to comply with the classical test theory (Lord & Novick, 1968).
4. A confirmatory, rather than exploratory, approach to validation should be used, which requires an a priori method for classifying measures of affect, behavior, and cognition.
5. All dependent measures must be scaled on a common evaluative continuum, reflecting an evaluative response toward the attitude object.

Fishbein and Ajzen (1975) argued that the affective, behavioral and cognitive components of attitudes are not empirically distinguishable. They have contended that the three-component terminology is inappropriate in its implication that the three types of responses are generally distinct. Furthermore, their research suggests that only a unidimensional model of attitudes is acceptable because all measures of attitudes order individuals along an evaluative continuum (Fishbein & Ajzen). Eagly and Chaiken (1993) challenged their argument, explaining that the tripartite model provides an important conceptual framework for evaluating three distinguishable attitude components that may be uniquely manifested through verbal responses. They further argued that the tripartite model may help researchers gain a better understanding of when and how these attitude components are salient.

Application of theory to tissue donation. When making a decision about tissue donation, there are two types of thought processes that can potentially be involved as suggested by the social psychology literature: automatic and controlled. Automatic or low-effort thinking can be defined as thinking that is “nonconscious, unintentional, involuntary, and effortless” (Aronson, Wilson, & Akert, 2003). Controlled or high-effort thinking is the other type of thought process which is defined as thinking that is “conscious, intentional, voluntary, and effortful” (Aronson et al., 2003). Both processes may be involved in decision-making. In the context of deciding to consent to or refuse tissue donation, a time characterized by a short window of time, high stress and emotionality, it is likely that automatic processes are primarily responsible for FDMs’ initial reactions to the request.

The automatic thought processes that occur at the time of a request for tissue donation are influenced by mental structures known as schemas. Schemas can be thought of as compartments of information, which are comprised of a set of beliefs and knowledge. Schemas may trigger the information that FDMs think about at the time of a request. Schemas also act as filters, separating out information that is contradictory to or inconsistent with the current theme (Fiske, 1993). With the exception of obvious inconsistencies, people are likely to notice and think about information that fit their preconceptions and ignore information that do not (Bodenhausen & Lichtenstein, 1987; Rothbart, Evans, & Fulero, 1979). This might explain why FDMs so often discredit TRs’ persuasive communication (e.g. refutations) which goes against their preconceptions about tissue donation (Siminoff, Traino, & Gordon, 2011). This phenomenon is otherwise known as the perseverance effect. Experimental studies have successfully illustrated the perseverance effect, explicating that people’s beliefs persist despite any debunking

evidence because the contradictory information prompts the brain to quickly (and nonconsciously) locate schemas and defend their beliefs (Anderson, 1995; Anderson & Lindsay, 1998; Davies, 1997). In the context of FDMs at the time of a tissue donation request, these schemas are still fresh in their minds, making any new information difficult to penetrate.

FDMs are especially likely to use schemas when they know very little, if anything, about tissue donation, which is often the case. An example of a schema FDMs might use is that of organ donation, perhaps that organ donation saves lives and is a great thing to do. If the belief is that organ and tissue donation is similar, the organ donation schema is activated and transposed onto tissue donation. FDMs then quickly judge tissue donation in a positive way. These time and labor saving shortcuts are known as judgmental heuristics (Aronson, Wilson, & Akert, 2003). Judgmental heuristics are applicable in the context of tissue donation where FDMs must make decisions in a short amount of time. There are three types of judgmental heuristics that FDMs may use: 1) availability heuristics, 2) representativeness heuristics, and 3) anchoring and adjustment heuristics.

The availability heuristic is a schema that comes to mind quickly and easily. It may involve attributing one's own personality traits to past behavior in order to make a judgment about oneself (Dougherty, Gettys, & Ogden, 1999; Manis, Shedler, Jonides, & Nelson, 1993; Rothman & Hardin, 1997; Schwarz, 1998; Tversky & Kahneman, 1973; Wanke, Schwarz, & Bless, 1995). For example, if an FDM has donated blood recently, this experience may come to mind and remind him/her of his/her altruistic nature, and s/he may therefore be more likely to donate tissues of their loved one. The representativeness heuristic is a judgment that uses a common example as a baseline for comparison (Tversky

& Kahneman, 1973). The clearest example of how this might apply to tissue donation is that FDMs think about tissue donation as being similar to organ donation since they both involve donation and are often presented together (ie. on driver's licenses, in PSAs, and campaigns). These similarities can influence an FDM to mentally "fit" tissue donation into their schemas on organ donation. Finally, the anchoring and adjustment heuristic is used when people adjust their set of beliefs based on a value that acts as an anchor (Tversky & Kahneman, 1974). This heuristic can also be based on an experience rather than a number and is related to accessibility and availability of schemas. An example may be if an FDM heard a TR early in their conversation use the word "harvesting" to explain the procurement of tissues. The FDM may fixate on the negative image this word provokes regardless of positive language used later in the conversation such as "tissue donation is a gift" or "tissue from just one donor can help 50 people". This rigid type of thinking is otherwise known as biased sampling, making a generalization based on one experience. Use of this heuristic often leads to mistakes in decision-making. Siminoff, Traino, and Gordon (2010) found that individuals who refused donation felt greater regret than families who donated two months later at the time of the interview ($p<0.001$). It may be that some of these FDMs quickly anchored their judgment about tissue donation on an isolated event to make their decisions and later realized this when they had time to think about it more. To summarize the above, people construct attitudes based on any currently known or observable attributes of the attitude object (Fazio, 1990; 1995).

The object appraisal function is the most primary of the attitudes function, especially accessible attitudes (Fazio, 2000). The stronger the object-evaluation association for a given object, the less work one does sizing up an object on presentation.

That is, people who are considering tissue donation but know little about it will look to associations to similar objects such as organ donation or medical care. If the individual has strong associations for the latter s/he should present with more definitive (i.e., stronger) attitudes toward tissue donation. The valence of those attitudes can be positive or negative. Making attitudes more accessible also makes decision making easier. For example, if you 'prepare' someone to consider a decision by priming them (having them practice an attitude), a decision will be easier (Fazio, Blascovich, & Driscoll, 1992).

The strength of an attitude toward tissue donation or of the association in memory between an attitude object (e.g. tissue donation) and its summary evaluation may vary. Moreover, as illustrated in Figure 1 above, an attitude toward tissue donation may derive from a combination of affect, behavior, or cognition (Fazio 1990; 1995). What this means is that an individual's initial reaction (or attitude) to the request for tissue donation may be comprised of any number of imaginable combinations of beliefs, which need not be mutually exclusive. In this context, beliefs refer to the information an individual has about tissue donation. In other words, beliefs contribute to attitude formation. Some beliefs may be stronger than others, meaning they have more influence on an individual's initial reaction. An affective belief may be "I feel squeamish about tissue donation". A behavioral belief may be "I've signed a donor card". A cognitive belief toward tissue donation may be "Old people can't donate tissues".

A study by Morgan, Stephenson, Harrison, Afifi, and Long (2008) of $N=4,426$ individuals from six different geographic regions across the U.S. found that noncognitive variables (e.g. affectively or behaviorally based variables) were more influential on the decision to donate organs than cognitive variables. The salient noncognitive variables

included the desire to keep the body intact, worries that signing a donor card might jinx a person, and medical mistrust. These authors coined the term “ick factor” for visceral responses to organ donation and the term “jinx factor” for fears surrounding premature death– both relating to the affective component of attitudes.

In a similar vein, Van Den Berg, Manstead, Van Der Pligt, and Wigboldus’ (2005) study has shed some light on the factors contributing to the attitudes of a group of individuals from the Netherlands who were unsure or undecided about OTD. A confirmatory factor analysis on 464 students revealed that affective evaluations of organ donation could be distinguished from cognitive and overall evaluations of organ donation. Affective evaluations showed ambivalence toward donation, whereas the other types of evaluations did not. Their findings suggest that affect plays a crucial role in attitudes toward organ donation. They also suggest that undecided attitudes toward organ donation may be due to affective ambivalence (Van Den Berg et al).

From a sample of audiorecorded request conversations between TRs and FDMs, it will be possible to extract FDMs’ affective, behavioral, and cognitive attitudinal responses, which will allow us to discriminate between FDMs by the initial reaction to the request (e.g., those who are initially favorable toward tissue donation, those who are initially unsure about tissue donation, and those who are initially unfavorable toward tissue donation). This may provide insight into how attitudes toward tissue donation are formed. Determining the attitude profiles of three types of FDMs is a necessary step in identifying the role that these attitude components play in FDMs’ decision to donate tissue. Not only will these efforts provide a deeper understanding of the process by which one decides to consent or refuse donation, but the results can be used to inform an educational

intervention that is based on the attitude profiles of FDMs from empirical data. Moreover, the knowledge generated herein may prove vital to further increasing the tissue donation consent rate in the U. S.

Assessing Attitudes Toward Tissue Donation

One way of conceptualizing attitudes is as a set of beliefs. Beliefs underlying donation decisions have been categorized as altruistic, religious, cultural, knowledge, and normative beliefs (Radecki & Jaccard, 1997). These types of beliefs have been frequently studied in research on attitudes toward organ donation. Altruistic beliefs derive from affective responses toward others and are widely associated in the literature with an increased willingness to donate. Religious beliefs have often been thought as obstacles to organ removal and include fears that organ donation prevents having an open casket funeral and that the absence of particular organs at the end of life will have repercussions in the afterlife (Radecki & Jaccard). Beliefs that are specific to particular cultures may be considered cultural beliefs although they are frequently reflective of religious beliefs as well. For example, Navajo Native Americans believe that body parts can be used to cause harm to an individual or his family through casting of spells (Phipps & True, 2001). Cultural beliefs are also beliefs that are shared by a group of individuals or a community. For example, in general, African Americans are more reluctant to donate organs and have reported religious fears, distrust of the medical establishment, and fear of premature death (Callendar, 1987; Minniefield & Yang, 2001; Siminoff & Sturm, 2000). Knowledge beliefs, which may be accurate or completely inaccurate, are those that are learned and often influence other types of beliefs. Finally, normative beliefs are based on an individual's

perception about a particular behavior based on whether significant others or members of the community would approve of the behavior (Fishbein & Ajzen, 1975).

Radecki & Jaccard (1997) synthesized the literature on FDMs' donation decisions for organ donation into two conceptual models, based on whether the deceased patient's wishes were known and unknown, respectively. If the deceased patient's wishes were known, the FDM's attitudes were primarily, and sometimes only, influenced by normative beliefs which reflected the deceased patient's wishes. If the deceased patient's wishes were unknown, the FDM's attitudes were influenced by many other factors than normative beliefs. For example, the four other types of beliefs mentioned above contributed to the FDM's attitudes toward organ donation. In addition, attributional beliefs, perceived emotional support, and beliefs about the medical profession were also salient.

Attributional beliefs reflect the probable wishes of the deceased patient based on the family's perception of existing information. Perceived emotional support is the connection the family perceives the medical staff to have with the patient. Also, this includes the belief that the medical staff understands their grief and has expressed general care for the patient (Radecki & Jaccard). Beliefs about the medical profession refer to the family's experience with the transplant team as well as their understanding of the terms used to describe the organ recovery.

Belief statements similar or identical to the five main beliefs described above from Radecki & Jaccard's (1997) literature review have been adapted by researchers to reflect attitudes toward tissue donation (Rodrigue, Scott, & Oppenheim, 2003; Siminoff, Traino, & Gordon, 2010; 2011). Researchers examining tissue donation have also had the added task of incorporating attitude statements that cover issues specific to tissue donation. Attitude

statements that have been measured in studies on tissue donation have included, “It is acceptable for donated tissue to be made into medical products (e.g. screws made from bone for surgical use)”, “Donor families should share in any money that is made through medical products made from donated tissue”, and “It is acceptable for tissues to be stored or packaged for long periods of time before their use”, for example. These statements relate back to information about the uses and consent process of tissue donation described earlier.

Studies have consistently found that individuals who have positive attitudes toward organ donation are more likely to donate their organs (e.g., Alvaro, Jones, Robles, & Siegel, 2005; Van Den Berg et al., 2005; Wakefield et al, 2010; Wu & Tang, 2009). Three studies found that negative attitudes or beliefs were a stronger predictor of willingness to donate than were positive attitudes or beliefs (Brug, Van Den Borne, Brouwers, & Van Hooff, 2000; Skowrowski, 1997). A review of the international literature from 1988 to 2009 showed that individuals who were younger, female, and had higher educational levels and/or socioeconomic status were more likely to have positive attitudes toward organ donation (Wakefield et al). Individuals who held positive attitudes also had fewer religious beliefs; higher knowledge levels; knew others with positive attitudes; were more altruistic and trusting; and had fewer concerns about disfigurement of the deceased donor’s body.

Studies exploring the motives or factors behind positive versus negative attitudes toward organ donation have mostly been limited by responses to surveys. Yet, by exploring outside of the traditional form of measurement, a few researchers have been able to advance the knowledge of the public’s attitudes toward OTD. For example, by using a research design that allowed participants to express both positive and negative motives at

the same time, Parisi & Katz (1986) discovered that only when negative motives were weak, were positive motives able to have an influence on individuals' overall attitudes in the positive direction of willingness to sign a donor card. In addition, Sanner (1994) has been one of the few researchers to have conducted qualitative research on the factors contributing to the public's attitudes toward organ donation. Through one on one interviews with 38 individuals who were either positive about donating organs, unsure or undecided about donating organs, and negative about donating organs, 600 statements regarding reactions to what may or may not be done to a deceased person in relation to donation were collected in open-ended unstructured interviews. These statements were narrowed down to 20 motive categories through the iterative process of qualitative content analysis. Of these categories, 17 were negative toward organ donation and 3 were positive. The categories were analyzed and interpreted in the context of psychodynamic defense theory – a theory used to explain defense mechanisms people use to cope with their anxiety surrounding death (p. 1141). Six motive complexes that could reasonably be explained by the theory emerged: 1) illusion of lingering life, 2) protection of the value of the individual, 3) distrust, anxiety, and alienation, 4) respecting the limits set by Nature or G-d, 5) altruism, and 6) rationality. These themes are consistent with Radecki & Jaccard's (1997) categorizations of attitudes, such as religious beliefs, altruistic beliefs, and possibly cultural beliefs.

Sanner's (1994) study presented some additional interesting findings. Individuals with negative attitudes toward organ donation were found to be either reacting out of anxiety surrounding death or by an existential belief about the afterlife. The negative motives of the individuals with overall positive attitudes toward organ donation were

derived from common death anxiety defenses. These death anxiety defenses were weakened, however, when presented with altruistic fact-stressing arguments. Of the 14 individuals in the undecided group, all but 3 individuals took a definitive stance either for or against donation by the end of the interview. With only 3 truly undecided individuals left, a detailed analysis of their motives could not be performed. Though this study contributed greatly to understanding the underlying motives of people's attitudes toward organ donation, it has only begun to scratch the surface of our knowledge on the motives underlying the public's attitudes toward organ donation, let alone tissue donation. Sanner recommended that future studies include a larger sample size to investigate whether these same reaction patterns occur.

Research studies on attitudes toward tissue donation have found similar results to those on organ donation. For example, Siminoff, Traino, and Gordon (2010) found that FDMs' attitudes toward and knowledge of tissue donation were significantly associated with families' donation decision (*Adjusted O.R.* = 10.0, 95% *CI* = [6.5, 15.5]). In a sample size of $N=1,418$, 78.4% of families who were initially favorable to the request consented to tissue donation; 18.7% of families who were initially unsure to the request consented to tissue donation; and 2.9% of families who were initially unfavorable to the request consented to tissue donation. These authors found that donor families reported significantly more favorable attitudes toward donation than nondonor families. Interestingly, donors and nondonors shared similar attitudes regarding the use of donated tissue for cosmetic purposes or involving for-profit companies in the processing and distribution of donated tissue. Nondonors incorrectly thought that tissue donors could not

have open casket funerals and that a signed donor card or a license marked “donor” did not apply to tissues or corneas (Siminoff, Traino & Gordon).

Families who were initially favorable towards tissue donation displayed more knowledge than families who were initially unfavorable. Moreover, families who were initially unsure about tissue donation shared more characteristics with families who were initially unfavorable than with families who were initially favorable (Siminoff, Traino & Gordon, 2010). Families who were initially unfavorable to the request were more likely to feel “squeamish” about the idea of tissue donation than families who were initially favorable. The strongest predictor of a family’s unfavorable response to a donation request was the belief that the patient would have been against tissue donation.

In Siminoff, Traino, and Gordon’s (2010), families were given the opportunity to elaborate in an open-ended format on reasons for their initial reaction to the request. Interestingly, some of these reasons matched up with their initial reaction toward tissue donation, while other unrelated reasons emerged. Factors that elicited donor families’ initial reaction to the request were reported as knowledge of the patient’s donation wishes, helping other individuals, and overall support of donation. The primary factor reported to elicit nondonor families’ initial reaction to the request was knowledge of the patient’s donation wishes (specifically that s/he did not want to donate). Additional factors included not wanting to put the patient through anything else, a belief that the patient’s tissues were unsuitable for donation, worry about the effect of procurement on the patient’s appearance, and a lack of knowledge about tissue donation (Siminoff, Traino, & Gordon). The information provided by the families’ responses to the open-ended questions shed light on their underlying attitudes toward tissue donation.

Where the Public's Attitudes Toward Tissue Donation Come From

The public's attitudes toward tissue donation may come from a variety of sources. The public may receive information about organ and tissue donation from public service announcements or campaigns that encourage individuals to declare their intention to donate organs at the DMV, an online donor registry, or have a discussion with family members about their donation wishes. The news media occasionally highlights successful and unsuccessful transplantation experiences. For example, the recent winner of TV show "Dancing with the Stars", J.R. Martinez, a victim of severe burns, was featured in popular news outlets such as, *CNN's Sunday Morning* and *60 Minutes*, and recognized for his resilience after receiving 33 cosmetic and skin-graft surgeries (Fager, 2003; Griffin, 2004). Accolades were given to tissue donors who provided skin grafts to make his surgeries and healing possible. His story highlighted the need for skin tissue donors to help other burn victims the way in which he was helped.

In a study on the influence of sources of organ donation information on public attitudes, Conesa et al (2004) administered organ donation attitude surveys to 2,000 randomly sampled members of the public and found that the source with the greatest influence on the public's attitudes was television. While television has certainly cultivated positive attitudes toward tissue donation as in the example above with the news media, it has generated or fed into the public's negative attitudes as well. Negative and fear-provoking information relayed through entertainment television shows, for example, may contribute to survey results that found exposure to donation information to have no significant effect on African Americans' intentions to donate organs (McNamara et al., 1999; Morgan, Harrison, Chewning, Davis, & Dicorcia, 2007). In an episode of *House*, a

patient received a transplant of a donated organ that was infected with Hepatitis C.

Episodes like these, while perhaps entertaining, magnify rare occurrences and perpetuate deep-rooted fears about the screening process of organs, for example. These fears often carry over to similar domains such as tissue donation (Morgan et al, 2005).

Conesa et al (2004) also found that the next greatest sources of influence, in order, were the press and radio, magazines and talks with friends/family, posters and campaigns about organ donation, and information given by health professionals. The only psychosocial variable that was associated with any of the sources of information was level of education. Sources that had a favorable effect on attitudes toward donation in general included discussions, ($p = 0.0079$), and information by health professionals ($p < 0.0005$), by friends ($p = 0.0132$) and by family ($p = 0.0044$) (for more information see Conesa et al, 2004).

Health care providers are especially influential on the public's attitudes toward tissue donation at the time when a request for donation is being made. According to Siminoff, Arnold, & Caplan (1995), health care providers' attitudes have a larger impact on the successful procurement of organs than their knowledge of donation. It has been found that health care providers' attitudes not only impact whether or not they speak with the families about donation, but when their attitudes are positive, families are much more likely to consent to donation (Siminoff, Arnold, & Caplan). Moreover, physicians' support for donation is the strongest predictor of other health care professionals' attitudes toward donation (Prottas & Batten, 1988). Studies have consistently found that U.S. physicians are less willing to donate their organs than the general public (Hobeika et al., 2009; Mandell et al., 2006; Prottas & Batten). The same has been found regarding health care providers'

attitudes toward tissue donation (Siminoff, Arnold, & Caplan). As the public often relies on medical professionals to lend advice and offer guidance, health care providers' negative attitudes influence families' attitudes (Haddow, 2004; Pelletier, 1992; Siminoff, 2001). In addition, though having nothing to do with donation, negative experiences at the hospital or with the patient's care can bias or influence families' attitudes toward tissue donation.

General news coverage, public service announcements, movies, television, family members, friends, medical professionals, and personal experience or involvement with donation are just some of the many sources where the public's attitudes toward tissue donation may come from (Conesa et al, 2004; Morgan et al, 2008).

When the Public's Attitudes Toward Tissue Donation are Formed

A multitude of factors are at play in determining when the public's attitudes toward tissue donation are formed. Many attitudes are learned through direct experience or through hearsay. Those that are learned through direct experience tend to be stronger and exert a greater influence on behavior (Fazio, 1990; 1995). For example, an individual who has received a tissue donation transplant is likely to have strong positive attitudes toward tissue donation. These positive attitudes will be more accessible and would strongly influence the individual's initial reaction to a request for the donation of a relative's tissues if she were to ever be in that situation. The same condition holds true for knowledge, self-interest, and social identification with tissue donation. Some people may form attitudes, positive or negative, toward tissue donation at a young age whereas others do not because the topic of tissue donation is personally relevant or intriguing. Whether attitudes are acquired through TV shows or personal conversations with friends, which may be providing false information, people's attitudes are strongly shaped by these initial

encounters. When the link between an attitude and an attitude object such as tissue donation is formed, it can become resistant to change. This is especially true for stronger links, and thus, stronger attitudes.

Radecki & Jaccard (1997) noted the important role individual differences play in determining when attitudes toward organ donation are formed. Individual differences are likely also important in determining when attitudes toward tissue donation are formed. An individual's ability to cope with stress as well as their ability to cope with death can affect whether or not new attitudes will be formed. For example, an individual experiencing a lot of stress and is unable to cope with that stress would not be able to formulate a new attitude toward tissue donation at that time. The importance of individual differences diminishes, however, in the context of tissue donation requests, as most families experience stress and their ability to cope is tested to some degree. This might help explain why most FDMs' are strongly influenced by their initial reactions or attitudes to consent or refuse tissue donation (Siminoff, Traino, & Gordon, 2010). It might also help explain why persuasion tactics are not entirely effective in changing FDMs' attitudes.

In other words, new attitudes toward tissue donation are not usually going to be formed at the time of a request for tissue donation due to high stress and difficulty coping with the death of a family member, among the other reasons described earlier. Therefore, it is important to intervene early before one experiences a request for their loved one's tissues. The next section of this review will delve into some of the efforts of researchers and organizations to target public attitudes through a variety of educational interventions.

III. Educational Interventions Targeting Public Attitudes

Several educational interventions have been designed to generate more favorable organ and tissue donation attitudes toward different populations. Descriptions of interventions implemented over the last 6-7 years are provided in Table 1. This table provides some insight into what has been done, what has been relatively successful, and where there are gaps in the literature in terms of types, samples, theory, and attitude measures used for OTD educational interventions. Examination of these characteristics can help guide the development of future interventions.

In general, there were a wide variety of interventions that have been implemented with various populations, but they mostly addressed organ donation. No interventions were found specifically on tissue donation. Prochaska and DiClemente's (1983) stages of change or transtheoretical model was the dominating theory which guided the interventions' design or outcome variables. While most of the interventions found significant changes in attitudes toward donation, their relative success is questioned. Attitudes were generally measured with only a couple of items that were predominantly cognitive-based. Moreover, it is not known whether some of these interventions are truly feasible and sustainable outside of a controlled experimental setting. As most of the interventions were designed with specific audiences in mind, it is also not known whether they are generalizable to other populations. Finally, only one intervention targeted specific attitude components (O'Carroll et al, 2011).

A Review of the Literature on OTD Attitude Change Educational Interventions

Over the past 20 years, many local and regional public education programs have been conceived and executed by numerous organizations. School-based classroom

interventions to promote positive attitudes toward OTD have been implemented in order to reach the country's youth, children and adolescents. The common assumption is that children and adolescents will be educated about these issues early and also act as a source of education to their families. In a high school with a diverse population, Cardenas, Thornton, Wong, Spigner, & Allen (2010) randomly assigned classes to an intervention group ($N=96$) or to a control group ($N=91$). Both groups were surveyed two weeks prior to the intervention and received the intervention, an educational session on OTD. The only difference between the intervention and control group was the order in which they received the intervention and a second follow-up questionnaire (ie. the control group completed the questionnaire before receiving the educational session). Students in the intervention group displayed a significant increase in knowledge and attitudes as compared to baseline.

A novel approach to increasing high school students' knowledge of and improving attitudes toward organ donation was undertaken by Vinokur, Merion, Couper, Jones, & Dong (2006) in a multi-media web-based intervention called "Give Life: The Transplant Journey". These researchers randomly assigned Michigan high school students to an experimental group ($N=152$) which provided educational material on organ donation and transplantation in a seven-step (seven-page) story which included the sequence of events from a fatal injury to death, followed by transplant donation, and an individual receiving a donated organ. It also included information on the need for and benefits of donation and transplantation, a persuasive argument for expressing one's intent to donate, and the need for communication of that intent to family members. Students ($N=159$) were also randomly assigned to a control group which provided educational material on methods to

avoid the common cold. Questionnaires measuring students' knowledge and attitudes were administered pre and post intervention. The authors found that there were significant increases in these measures for the students in the experimental group compared to students in the control group.

Community-based interventions have also been implemented that target specific groups of people, such as ethnic minorities, who generally have less favorable attitudes toward OTD than their white counterparts (Rubens, 1996; Siminoff et al, 2001; Siminoff, Lawrence, & Arnold, 2003; Wakefield et al., 2010). Project (ACTS) About Choices in Transplantation and Sharing, for example, sought to increase OTD intentions which may be conceptualized as similar to the behavioral component of attitudes among African Americans. Participants from nine churches were randomly assigned to a control group ($N=162$) or to an intervention group ($N=175$). The control group received organ and tissue donation education materials that were currently available to consumers which included mainstream pamphlets and videotapes. The intervention group received Project ACTS educational materials which included Project ACTS pamphlets and videos. The Project ACTS materials included health messages with religious themes which were informed by a Community Advisory Board (CAB), a group consisting of key stakeholders in the community. The CAB for this particular study was comprised of African American religious leaders and individuals with expertise in organ and tissue donation, transplantation, and mass media communication. The primary outcomes, assessed at the 1-year follow-up, were readiness to express donation intentions by designating oneself as a donor, and family discussion about organ and tissue donation. Results indicated a significant interaction between condition and time on readiness to talk to family. Participants in the

intervention group were 1.64 times more likely to be in the action or maintenance stage of change at follow-up than the participants in the control group, ($p=0.04$).

Callender, Bey, Miles, and Yeager (1995), pioneers of a successful OTD program called the Minority Organ Tissue and Transplant Education Program (MOTTEP), encouraged using community stakeholders in the planning and implementation of education programs. Tests of the MOTTEP approach have been successful. For example, using this approach with a sample of Native Americans and Alaskan Natives, Callendar, Hall, & Branch (2001) found a significant improvement in deceased donation attitudes, knowledge, beliefs, and intentions. Building on this approach, Fahrenwald, Belitz, & Keckler (2010) recently evaluated the outcome of an educational intervention on OTD for Native Americans called, “Sharing the Gift of Life”, and found similar success. A CAB chose intervention strategies derived from the oral tradition of story-telling. Their program consisted of both written materials and an instructional video which reflected the value of generosity as opposed to the values of wealth and power so commonly seen outside the reservations. Stage of motivational readiness (SMR) to serve as a deceased donor, as represented in the transtheoretical model (Prochaska & DiClemente, 1983), was the primary outcome. The transtheoretical model consists of five stages (pre-contemplation, contemplation, preparation, action, and maintenance) and describes how an individual moves from one behavioral stage to the next prior to performing a behavior. Each stage can be measured separately. In this study, SMR was measured for all five stages. The participants’ progression in SMR from pre-test to post-test was significant ($\chi^2 (1, 1580)=18.32, p<0.05$), indicating an overall positive change in their deceased organ and tissue donor intentions.

Siegel et al (2010) developed an intervention for individuals who are positive about donation but have yet to designate themselves as donors (otherwise known as “passive-positives”). Research demonstrating that most people have positive weak attitudes as a result of low interest and attitude ambivalence (Siegel & Alvaro, 2010; Siegel, Alvaro, Lac, Crano, & Dominick, 2008) pointed the authors toward an intervention for a passive-positive audience that would adequately address these issues. Guided by the Immediate opportunity, Information, Focused engagement, and Favorable activation (IIFF) Framework, Siegel et al (2010) conducted interactive discussion groups in a quasi-experimental, four-city (Miami, Phoenix, Chicago, and Seattle), pretest/posttest design with the goal of finding a significant increase in organ donation registration rates among the intervention groups. The IIFF framework was specially designed for “passive-positive” individuals as it specifies that an intervention geared toward this group should provide an opportunity to register (ie. provide donor registration forms); should provide adequate information to dispel any myths; should captivate their attention on the issues surrounding organ donation; and should steer individuals’ attitudes in a favorable direction toward organ donation. The two-hour discussion groups included a discussion on the question, “Why have you not registered prior to today?” and the inclusion of a donor card registration form with the post-questionnaire. Of the individuals who were assigned to the focus groups, 46% had registered by the end of the focus groups. Interestingly, retrospective analyses of the pre-attitudinal questionnaires and post-registration behavior revealed that individuals who reported lack of knowledge or lack of opportunity to register signed up to be organ donors at a rate of 63.6%. Individuals who reported not registering

due to discomfort with thoughts of death or a fear that life-saving measures would not be used in an effort to procure their organs signed up to be organ donors at a rate of 5.8%.

Other interventions have included educational materials for specific hard-to-reach populations. An Ohio OPO, for example, designed a unique brochure for unregistered rural and urban Ohio residents identifying how to overcome barriers to organ and tissue donation (Health Resources and Services Administration [HRSA], 2011). In a similar vein, an age-tailored marketing message is being delivered to 50-65 year olds in several geographic areas by the OPO LifeNet in Virginia. The messages are designed to change perceptions about who can donate organs and tissues. Specifically, messages addressing the false belief that people over the age of 50 are medically unsuitable to donate are included. The message and the medium of delivery will soon be evaluated with behavior change and donor registration rates as outcome measures.

Individuals who have discussed their donation wishes with family members are much more likely to be donors upon death than individuals without such discussions or documentation. OTD researchers have thus developed interventions to improve and increase the number of family discussions surrounding organ donation (Siminoff, Arnold, & Hewlett, 2001). Some interventions have included role-play techniques to increase self-efficacy and skills for having discussions about organ donation. For example, Lifeline, Ohio's OPO, has recently piloted a program called "Can We Talk?" which seeks to increase organ donation registration among older adults (HRSA, 2011). The program will achieve this aim through a dialogue that involves participants in an interactive discussion. It specifically targets adults who have not declared their donation intentions, but who have

positive attitudes toward organ donation (positive potential non-consenting adults). The results have yet to be published.

Some researchers have implemented work-site interventions to change employees' attitudes toward organ donation. Quinn, Alexander, Hollingsworth, O'Connor, & Meltzer (2006) provided a "Lunch-and-Learn" information and skill-building session to corporate employees located in the metropolitan Chicago area. Testimonials from transplant recipients were included in the session with the intent of tapping into the affective component of attitudes. Participants were randomly assigned to two educational interventions, basic ($N=254$) and advanced ($N=288$), as well as to a control group ($N=213$). Outcome variables included intention to be an organ donor (which can be thought of as or a proxy to the behavioral component of attitudes), communication with families, and documentation of organ donation wishes. Both interventions were effective in changing participants' intentions to become organ donors as only 3% of these individuals were still in the precontemplation stage (according to the transtheoretical model) as compared to the 12% that were there at baseline (Quinn et al.).

Researchers have sometimes capitalized on attitude research and theory to guide the development of educational interventions on OTD rather than studying whether their interventions have changed attitudes. An example is an intervention which used posters with various message appeals to increase the number of individuals who registered as organ donors at computer kiosks. Through a quasi-experiment, they found that counterarguments were the most efficacious message appeals, especially in academic settings; whereas, emotional message appeals were most successful in hospital settings ($p's < 0.001$) (Siegel et al, 2008).

Another study measured cognitive and affective attitudes and assessed the role they play in the decision to become an organ donor. O'Carroll, Foster, McGeechan, Sandford, & Ferguson's (2011) UK study explored the role of cognitive attitudes and affective attitudes stemming from Morgan et al's (2008) study (e.g. the "ick factor", the "jinx factor", and medical mistrust) in donation behavior. In a sample of 621 participants, nondonors were not significantly different from donors in terms of their cognitive attitudes. The authors also found that nondonors scored significantly higher than donors on the affective "ick" factor and bodily integrity scales. Moreover, the authors tested whether a manipulation of anticipated regret would affect nondonors' intention to register as an organ donor. The intervention group ($N=103$) received two additional questions than the control group ($N=90$). One question, "If I didn't register as an organ donor and someone I cared about died that could have been saved, I would feel regret", was placed as the first question in the survey and the other question, "If I don't register as an organ donor I will later wish that I had", was placed immediately before a question measuring intention to donate. They found that the anticipated regret manipulation led to a significant increase in nondonors' intention to register as an organ donor in the future. These findings suggest that negative affective attitudes influence individuals to not register as organ donors. They also suggest that future interventions should include anticipated regret messages as a way of increasing organ donation rates.

Table 1

Examples of OTD interventions that target public attitudes from 2006-2012

Reference	Type of intervention/ Name/ <i>Organs</i> , <i>tissues</i> , or <i>both?</i> *	Theoretical Framework	Study Design	Sample Characteristics	Attitude Measures	Outcome Variables	Findings
Cardenas, Thornton, Wong, Spigner & Allen, 2010	Didactic classroom session; <i>Organs</i>	None mentioned	Randomized controlled trial	Asian American and African American high school students in urban Seattle, WA (N=187)	Single item measure with a four-point continuum	Knowledge, willingness to donate organs	<ul style="list-style-type: none"> • Intervention group had significant increase in knowledge scores ($p<0.001$); increase on willingness to donate ($p<0.0001$) • Ethnicity and gender did not significantly predict opinion at post-test
Vinokur, Merion, Couper, Jones, & Dong, 2006	Multi-media enhanced website called "Give Life: The Transplant Journey" (www.journeytransweb.org/reviewthejourney); <i>Organs</i>	Theory of Reasoned Action (TRA) and Theory of Planned Behavior (TPB)	Randomized controlled trial; pretest/posttest design	High school students from 81 schools in Michigan (N=490)	Three item prodonation attitude measure with a 7-point Likert scale with 1=definitely do not want to, and 7=definitely want to	Knowledge of and attitudes toward organ donation, contact of donor registry	<ul style="list-style-type: none"> • Statistically significant increases in knowledge of and attitudes toward organ donation from pre to post test in the experimental group compared to the control group • Increases in knowledge and prodonation attitudes mediated the effects of the intervention on contacting the donor registry

Arriola, Robinson, Thompson, & Perryman, 2010	Culturally sensitive and family-focused; Project ACTS (About Choices in Transplantation and Sharing); Both	Transtheoretical Model and Stages of Change	Randomized controlled trial	Church-going African Americans (N=425)	Three item measure with a five-point responses corresponding to the five stages of change	OTD intentions, readiness to donate organs and tissues	<ul style="list-style-type: none"> Intervention group 1.64 times more likely to be in action or maintenance stage of change at follow-up than control group ($p=0.04$).
Siegel et al, 2010	Discussion groups; Organs	IIF model	Quasi-experimental pre-test/post-test design	American "passive positive" nondonors (N=131)	Pre only: Open-ended question on reasons for non-registration; Pre and Post: Two item measure with a 7-point Likert scale from 1=strongly disagree to 7=strongly agree	Deceased organ donation attitudes, knowledge, intentions, and registration behavior	<ul style="list-style-type: none"> Intervention group had 46.6% of individuals sign donor cards
Fahrenwald, Belitz, & Keckler, 2010	Community-based participatory approach; brochure paired with outreach coordinator, video, and booklet; Sharing the Gift of Life; Both	Transtheoretical Model and Stages of Change; Tailored MOTTEP	Pre-test/post-test design	Native Americans in Northern Plains region of the U.S. (N=1580)	[Stage of motivational readiness or SMR measure] Single item with three responses	[Intention measure] SMR to serve as a deceased organ and tissue donor	<ul style="list-style-type: none"> Overall positive change in participants' donor intentions ($p<0.05$) Attitudes not measured, but theoretical constructs like decisional balance incorporated into intervention messages

Quinn, Alexander, Hollingsworth, O'Connor, & Meltzer, 2006	Work-place information and skill-building "Lunch-and-Learn" session with transplant recipient testimonials; Organs	Transtheoretical Model and Stages of Change	Randomized controlled trial with two types of interventions	Corporate employees in the Chicago metropolitan area (N=754)	[Intention measure] Single item five-point responses corresponding to the five stages of change	Intention, communication, and documentation to be an organ donor	<ul style="list-style-type: none"> • Both interventions similarly effective in changing intention to be organ donors ($p=0.001$) • Percentage increase in donor card signing significant for both intervention groups ($p<0.002$) but not for control group ($p=0.454$)
Siegel et al, 2008	Poster message appeal variations; Organs	Concepts studied by past researchers	4 (Appeal) x 4 (Exemplar) x 4 (Location) counterbalanced quasi-experimental design	Convenience sample of adults (N=421)	None, though messages were developed from attitude change research	Number of registered organ donors	<ul style="list-style-type: none"> • Counterargument most efficacious, especially in academic setting; Emotional appeal most successful in hospitals ($p's<0.001$)
O'Carroll, Foster, McGeechan, Sandford, & Ferguson, 2011	Questionnaire; message manipulation on affective and cognitive attitudes; Organs	Morgan et al's (2008) five-factor theory on attitudes; Theory of Reasoned Action (TRA)	Three experiments	Adult students and staff, both donors and nondonors, at three universities in the U.K. (N=621)	16 item measure scored on a 7-point Likert scale from 1=strongly disagree to 7=strongly agree; Adapted from Morgan et al (2008)	Intention to register as an organ donor, affective and cognitive attitudes toward organ donation	<ul style="list-style-type: none"> • Nondonors scored significantly higher than donors on affective "ick" factor and bodily integrity scales ($p<0.0001$) • Significant increase in nondonors' intention to register as organ donor in future with anticipated regret message ($p=0.008$)

*Note. *Organs, tissues, or both?* refers to whether the intervention's focus was on organ donation, tissue donation, or both organ and tissue donation.

Filling in the Gaps: An Intervention Targeting Attitudes Toward Tissue Donation

There have been a variety of OTD educational interventions involving attitude change or theory from classroom sessions to message appeals. Although many were effective in improving their intended outcome measures, some limitations can be noted. As we can see in Table 1, there is seemingly frequent use of the transtheoretical or stages of change model in this sample of interventions. This theoretical paradigm is perhaps not most suitable for effecting change in attitudes and behaviors toward organ donation. One of the major assumptions of the transtheoretical model is that individuals make stable and coherent plans, yet research on organ donation has shown that individuals' plans or intentions to donate organs is not usually consistent with their behavior (Feeley & Servoss, 2005; Radecki & Jaccard, 1997). Research on tissue donation has shown a similar pattern (Siminoff, Traino, & Gordon, 2010; 2011). In addition, while interventions using the transtheoretical framework may have illustrated some success, the reality is that the rate of tissue donation has not significantly increased in years (Siminoff, Arnold, & Caplan, 1995). Using a different theoretical framework for OTD interventions could give rise to new, creative, and more effective ways of changing attitudes toward tissue donation. The tools used to measure attitudes toward organ donation were limited in that they were comprised of few items and mostly assessed only the cognitive component of attitudes. A major assumption among these interventions that may be flawed is that the participants are motivated to receive the message and have the ability to process the information. Furthermore, to the best of our knowledge, only one study explicitly had any mention of attitude components; most of the interventions targeted non-specific attitudes (O'Carroll et al, 2011; Rosenberg & Hovland, 1960).

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While many significant contributions have been made toward increasing the number of people on donor registries and toward encouraging people to discuss their OTD wishes with their families, the actual consent rates for tissue donation have barely increased as compared to those for organ donation (Kent, 1997). This may be due to the fact that most interventions are directed at organ donation. To the best of our knowledge, none have been designed to change the public's attitudes toward tissue donation.

Education to correct public misconceptions about tissue donation may prove successful in increasing consent rates; however, it may not be a "one size fits all" approach. Most OTD educational programs have not been national in scope, consistent and sustained, nor have they engaged the public in their continuation (Callender, Bey, Miles, Yeager, 1995).

Callender, Bey, Miles, and Yeager (1995) gave two main recommendations for a successful intervention: 1) a unifying national theme, and 2) local efforts building on the national theme.

Reflecting on possible alternative explanations for the weaker findings from some of the educational interventions on organ donation not presented here may advance previous thinking on how to modify public attitudes toward tissue donation. It is possible, for example, that previous educational campaigns have successfully altered community attitudes but did not result in an increase in actual donor numbers because the intervention solidified the community's acceptance of making a firm decision against donation rather than for donation (Wakefield et al, 2010). It is also possible that previous educational interventions have successfully imparted relatable facts to the public, but have failed to help people work through their anxiety about some of these facts. As Sanner (1994) found, anxiety (and probably other equally significant affective components) affects

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attitudes toward tissue donation. Therefore, it is not only important to impart information, but to also help people come to terms with their partly subconscious and not always clearly articulated uneasiness about tissue donation.

With any educational message, there is a risk that individuals may suppress uncomfortable ideas and, thus, dodge thoughtful and controlled thinking about tissue donation (Roemer & Borkovec, 1994). Individuals may block information on the topic or even distort or misrepresent any such information in an effort to escape cognitive dissonance, a discomfort caused by having conflicting cognitions (Festinger, 1957; Roemer & Borkovec). OTD campaigns have mostly targeted people who are considered highly involved (e.g., have high exposure to or motivation towards OTD) or have a high need for cognition (Caccioppo & Petty, 1982). It is important to also target those who may feel initially uncomfortable with or have negative attitudes towards the idea of tissue donation. Research has shown that most of the initial discomfort subsides with additional information (Ajzen, 2001). Aldridge, Guy, & Roggenkamp (2003) recommended using personal selling, or caring personal appeals for a low involvement audience. Anticipated regret messages may also be used to change initial attitudes, as they changed individuals' intentions to register as an organ donor in O'Carroll et al's (2011) intervention study.

An intervention or message targeted to individuals who are initially unsure or unfavorable toward tissue donation, guided by social marketing research on audience segmentation, should stimulate controlled thinking for deeper elaboration on the various aspects of tissue donation (Slater, 1995). The heuristic-systematic dual process theory expounds upon the concept of controlled thinking, specifically in that heuristics can trigger controlled (or systematic) thinking (Chaiken & Trope, 1999; Dillard, 2002; Eagly & Chaiken,

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1993) in addition to automatic (or heuristic) thinking. This theory may provide useful framework for developing an educational intervention on tissue donation to change or encourage attitudes in the direction of consent.

These ideas may not only aid in the development of a new intervention to change attitudes toward tissue donation, but they may also point to the utility of identifying the components of FDMs' attitudes toward tissue donation beforehand in order to sensitively design an intervention. By identifying the more modifiable and specific individual attitude components put forth in the tripartite model, it will be possible to develop and tailor an educational intervention to the public's needs.

Chapter III. Specific Aims

This study seeks to understand the public's attitudes toward tissue donation. First, we drew on the classical tripartite model of attitudes to understand the process of how attitudes toward tissue donation are formed. Next, we assessed the differences between families' attitudes based on their initial reaction to the tissue donation request. Finally, we used this information to develop a suggestion for an educational intervention that aims to modify attitudes toward tissue donation in an effort to increase the tissue donation consent rate.

Therefore, the specific aims of this study were:

Specific Aim 1: Understand attitude formation and how attitudes toward tissue donation are developed. A qualitative coding approach informed by the Tripartite Model of Attitude Structure was developed and utilized to describe the attitude components of individuals asked to donate a family member's tissue. The two perspectives examined were:

- a. **Tissue requesters** – Semi-structured interviews were conducted with tissue requesters to elicit their perceptions of families' attitudes toward tissue donation.
- b. **Families** – Audiorecordings of requests with families of newly deceased individuals who were asked to donate tissue were examined to determine families' expressed attitudes toward tissue donation.

Specific Aim 2: Assess the differences in attitude components between three groups of families (initially favorable, unsure, and unfavorable). Using the attitude domains

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developed in Specific Aim 1 as outcome variables, MANCOVA was performed to assess whether the means of the attitude components were different between FDM groups.

Specific Aim 3: Develop a suggestion for an educational intervention to change the public's understanding of and attitudes toward tissue donation. The results from Specific Aims 1 and 2 were used to inform a suggested educational intervention, which was developed with guidance from the TRs.

Chapter IV. Methodology

Overview

Primary data from interviews with tissue requesters (TRs) on their perceptions of family decision-makers' (FDMs') attitudes toward tissue donation was collected. Secondary data from Siminoff's parent study (described below) was used to examine FDMs' attitudes. Together, the two perspectives, of the TRs and the FDMs, aided in accomplishing Specific Aim 1: to understand how attitudes toward tissue donation are developed. Quantitative analyses were conducted to accomplish Specific Aim 2: to distinguish three groups of FDMs based on their attitudes. Finally, the results from Specific Aims 1 and 2 were used to accomplish Specific Aim 3: to develop a suggestion for an educational intervention targeting the public's attitudes toward tissue donation.

Parent Study

This dissertation is based on a parent research study conducted by Siminoff (AHRQ Grant #: R01 HS-13152) that sought to identify determinants of families' consent to tissue donation. The parent study included multiple sources of data, which were used herein to achieve the dissertation's goal of understanding the public's attitudes toward tissue donation. The parent study includes data collected from 2003 to 2006 of audiotaped request conversations between tissue requesters and family decision makers from a national sample of 16 tissue banks. Select emotional content codes and relational communication codes, developed in the parent study from the Siminoff Content Communication & Affect Program (SCCAP), a program designed specifically for the purpose of coding and analyzing conversational data, were included in the analysis portion of this dissertation (Siminoff & Step, 2011). From the audiorecordings, new codes were created

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through a qualitative coding approach in order to tap into attitudinal components of FDMs' attitudes as outlined by the Tripartite Model of Attitude Structure.

Another source of data from the Siminoff parent study came from the family surveys/interviews conducted with the FDMs in the audiorecordings. The family surveys/interviews consist of both structured and semi-structured questions. The first part includes questions on topics of sociodemographics, the quality of care the patient received at the hospital, interactions with the tissue bank requestors, families' general attitudes and beliefs, and their donation decision. The second part consists of open-ended responses on FDMs' specific attitudes, including the reasons why they were initially favorable, unsure, or unfavorable to the request for donation; the reasons why they thought the patient would not want to donate tissue; and the reasons why they decided what they did. Several variables from the family interview data, some of which measure attitudes and some of which measure sociodemographics, were selected for this dissertation. Finally, TR staff from the various tissue banks who requested tissues from the FDMs completed surveys about the FDMs and topics covered during their conversations. Only one variable from the TR surveys was used in this study. A complete list of the variables and their sources can be found in Table 4 and will be discussed in greater detail.

Specific Aim 1: Understand attitude formation and how attitudes toward tissue donation are developed

In order to accomplish Specific Aim 1, two different perspectives were sought, the FDMs and the TRs. Specific Aim 1 first examines the TR perspective and then the FDM perspective.

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I. TR recruitment site. TRs were recruited from LifeNet Health, a federally recognized Organ Procurement Organization (OPO) that provides organ and tissue recovery services for a large portion of the state of Virginia and part of West Virginia, servicing a population of approximately 5.2 million people and over 80 hospitals (lifenethealthopo.org). LifeNet Health has a tissue donation call center located in Virginia Beach, Virginia, where Transplant Coordinators or TRs receive referrals for tissue donation requests from hospitals, medical examiners offices, and various other sources. The call center is where TRs were recruited for this study. Permission was received from the Director of the Donor Center to recruit TRs and conduct interviews either during or after their working hours. IRB approval from VCU was received prior to the conduct of any recruitment and interviews (IRB # HM14351).

TR sample. Of 18 potential TRs to recruit, 4 declined participation and 14 (77.8%) TRs agreed to an interview about their perceptions of families attitudes toward tissue donation. TRs based their responses on their professional experiences requesting tissue donation from families via telephone. TRs were eligible if they worked full-time and were fully trained and actively making requests. Individuals still in training were excluded from participation as we were interested in speaking with TRs who had enough experience to draw from about families' attitudes toward tissue donation. All TRs who participated in this study were at least 18 years of age or older.

TR recruitment. In December 2011, a 30-minute presentation was provided to the TRs during a monthly staff meeting. The presentation included the overall goals of the study, the TRs' potential contributions, how confidentiality would be maintained, and generally what participation in the study entailed. TRs were also made aware at the

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presentation and also before the interviews that compensation would not be provided for participating in the study but that their participation would advance research in their field, specifically on the public's attitudes toward tissue donation. Flyers with key points about the study and the researcher's contact information were provided. The flyer was posted on the call center's bulletin board as a reminder about the study and to inform TRs who were not able to attend the presentation. TRs were offered the opportunity to opt-in by providing contact information (e.g., names, email addresses, phone numbers, and preferred method of contact) on a sign-up sheet. A few months after the presentation, the researcher followed up with 10 TRs who opted-in by email or telephone. In the emails and telephone calls, TRs were reminded about the study and asked if they were still interested in participating in the study. All 10 were still interested in participating and times and interviews were scheduled with the assistance of the call center Supervisor. Since TRs work two 12-hour shifts, from 7am to 7pm and from 7pm to 7am, the first 10 interviews were scheduled in 3-4 hour blocks during changes in shifts. These interviews were conducted over a three-day period in May, 2012. During this visit, the call center Supervisor assisted by speaking with the other TRs on duty to recruit into the study. The Supervisor also reached out to TRs not on duty concerning participation in the study. Four more interviews were conducted in July 2012.

Data collection. Semi-structured interviews were the methodology of choice for assessing TRs' perspectives on FDMs' attitudes toward tissue donation as they provide a means to obtain the TRs' "subjective understanding" of the topic as they are experts in the field of tissue donation (Corbin & Strauss, 2008). In addition, semi-structured interviews provide some direction for TRs to offer insight into the research question while at the same

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time allowing for themes and topics to naturally emerge while assuring that all subjects considered the same issues. In-person interviews were preferred as they have been shown to be especially conducive for developing rapport, which is helpful when conducting formative research (Chirban, 1996). TRs added a valuable perspective to this study as they have privileged access to the FDMs. Moreover, TRs can be considered experts in the field of tissue donation as they have spoken to hundreds of families about donating their loved ones tissues and were able to provide a direct lens into the research topic under investigation. (Corbin & Strauss, 2008).

Interview guide. An interview guide, or a list of questions to guide the interviewer during the interview, was developed under the guidance of Dr. Laura Siminoff, an expert in the field of tissue donation (see Appendix A for a copy of the Interview Guide). Topics included the TRs' perceptions of FDMs' knowledge about tissue donation, the kinds of attitudes toward tissue donation expressed by FDMs, common misconceptions about tissue donation heard during requests and strategies commonly used to overcome wrongly held beliefs about donation, and issues brought up by families who are initially favorable, unsure, and unfavorable toward tissue donation. Also, there were questions about TRs' thoughts and suggestions on important messages to include in an educational intervention, specifically, recommendations regarding groups of people they might target and why.

Interview procedures. Semi-structured interviews were conducted with TRs at the LifeNet Health call center in a private room away from the call center in order to avoid any distractions and to maintain confidentiality. Informed consent was obtained prior to conducting any interviews. Interviews were audiorecorded and lasted anywhere from 15 to 45 minutes. All 14 TRs interviewed agreed to having their interviews recorded.

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Questions were asked consistently across the interviews. At the end of the interview, the first 8 TRs interviewed were asked if they could be contacted a few months later to provide feedback on the coding scheme to be discussed later. All 8 TRs agreed to be re-contacted.

Coding of TR interview data. A qualitative content analysis approach for the open-ended responses from the interviews was used to identify domains and subdomains central to the topic under study. This approach explores the perceptions of a particular phenomenon. Moreover, it allows a researcher to “adapt” theory (e.g. Tripartite Model of Attitude Structure) to the transcripts at hand (Corbin & Strauss, 2008; Krippendorff, 2004; Rosenberg & Hovland, 1960). Thus, qualitative content analysis aligned well with the goal of the interviews: to understand the TR’s perceptions of families’ attitudes toward tissue donation. The process entailed immersion, reduction, and interpretation of the data (Forman & Damschroder, 2008). Immersion involved reading through the transcripts of the conversations several times in order to become familiar with the data and identify themes. The reduction phase included creating initial codes, developing a coding scheme and codebook, and coding the interviews.

A preliminary coding scheme was developed early in the analysis process (after coding 5 transcripts). As coding was an iterative process of assigning the responses to open-ended interview questions to different categories, the coding scheme was revised several times as new themes emerged. Finally, data interpretation consisted of generating themes and subthemes from the assigned codes (or domains and subdomains) which were organized around questions from the interview guide that pertained to the study’s theoretical framework (Forman & Damschroder, 2008). Interpretation also consisted of an audit trail with memos, or documentation of the coding decisions made (Corbin & Strauss,

2008). The final coding scheme or instrument used to code the TR interviews and the Coding Manual for TR Interviews can be found in Appendices B and C, respectively.

LifeNet Health TRs who agreed to recontact were recontacted to provide feedback on the coding instrument. Two TRs responded and provided feedback on some of the codes. This feedback was incorporated into the final TR coding instrument. Their review of the instrument helped to ensure its face validity.

The TR Coding Instrument was developed from the TR Interview Guide described above. Additional questions for the TR Coding Instrument were generated from the themes and codes identified in the interview transcripts. For example, question 3 asks, "What knowledge do families lack?" While this question is not on the interview guide, coding of TRs' responses to the question, "What knowledge do families have?" gave rise to the question about what knowledge families lack as it was a commonly discussed topic. ATLAS.ti version 7.0, a computer software program for qualitative data management and organization, assisted in coding the TR interviews and subsequently, developing the coding instrument (Muhr, 1997). The TR Coding Manual with instructions on coding and using the coding instrument as well as definitions for the codes were developed alongside the coding instrument.

Interrater reliability for TR interview coding. After all of TR interviews were coded, 2 (10%) interviews were double coded by a student coder. Cases were randomly selected for double coding using a freely available online tool called Research Randomizer (Urbaniak & Plous, 2011). Interrater reliability, calculated by the percent agreement between the coders' codes for the TR interviews, was 0.94.

II. FDM sample. To identify and understand the expressed attitudes of individuals asked to donate tissues, the audiorecordings of request conversations between TRs and FDMs from Siminoff's study were examined. The FDMs were identified from sixteen different tissue banks across the United States that agreed to participate in the parent study. Tissue banks were randomized to specific data collection days from which the FDM sample was comprised. FDMs were spouses, children, parents, siblings, relatives, significant others, or legal guardians of patients and were contacted by telephone a few hours after the death of their loved ones.

The sample for this study was drawn from an original sample of 1,016 FDMs, more specifically, 533 (55.4%) FDMs were initially favorable, 221 (23%) FDMs were initially unsure, and 164 (17%) FDMs were initially unfavorable. A randomized stratified sample from the original dataset was drawn with the assistance of Research Randomizer mentioned above (Urbaniak & Plous, 2011).

The sample of audiorecordings ($N=240$) for this study was comprised of three types or groups of FDMs classified according to their initial reaction to the request for tissue donation which was assessed in the family interview: 1) those who were initially favorable to the request ($n=80$), 2) those who were initially unsure about the request ($n=80$), and 3) those who were initially unfavorable to the request ($n=80$). These FDM attitude classifications have been reported in previous studies and have been shown to strongly predict consent behavior (Siminoff, Traino, & Gordon, 2010; Siminoff et al, 2001; Weathersbee & Maynard, 2009).

Power calculation. GPower 3.1.3. software (Faul, Erdfelder, Lang, & Buchner, 2007) was used to determine the sample size needed to achieve sufficient power for

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multivariate analyses in Specific Aim 2. These calculations supported the decision to include 80 per group for a total of 240 to obtain power of at least 0.90 and an effect size as low as 0.04 with an alpha of 0.05.

Development of FDM coding instrument. Three categories of attitudes, affective, behavioral, and cognitive, were coded from the recordings. Examples of attitude statements and questions that were coded are provided in Table 2. To recap, affective attitudes are the emotional reactions to the attitude object; behavioral attitudes reflect any interaction with the attitude object (e.g., the tendency to act in certain ways toward tissue donation); and cognitive attitudes consist of the beliefs or expected values an individual expresses, sometimes in the form of a stereotype.

Table 2

Examples of extracted attitude statements/questions of FDMs that were coded

Attitude component	FDM statement
Affective	"I'm glad someone will get some use out of his/her tissues." "I'm not really comfortable with donation."
Behavioral	"I'm a donor myself." "I discussed donation with him/her [patient]."
Cognitive	"I don't think anyone would want his tissues." "Will s/he [patient] still look the same?"

Of the $N=240$ audiotapes, approximately 30 FDM audiotapes (10 from each group) were reviewed in order to generate the domains and subdomains that would be the foundation for the FDM coding instrument. The sample size of 30 was chosen on the basis of procedures used by previous studies where saturation was reached and on expert recommendation (Griffin, Chung, Tzortziou-Brown, & Morrissey, 2011; Patton, 2002).

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As with the interview data from the TRs, a qualitative content analysis approach to identify themes that fit with the Tripartite Model of Attitude Structure was employed for the FDM audiofiles (Corbin & Strauss, 2008; Rosenberg & Hovland, 1960). Emergent themes that were outside of the theoretical framework were also included as a separate “Other Attitudes” category. The attitude statements were grouped together and reduced into codes. At this point, the immersion phase required carefully listening to and re-listening to the audiotapes to recognize themes. The data reduction and interpretation phases were similar to the process used for the TR interview data; it was an iterative process, entailing revising, re-grouping, adding, and deleting of codes. ATLAS.ti was used to assist with this process. Reliability and validity of codes was ensured through discussions with the study’s advisor and one of the committee members.

By assessing the FDMs’ perspective through this process, it was possible to triangulate the data and data sources, and enhance the qualitative rigor of this study. The rationale for using the same approach for this data as the TR interview data was that it allowed for the comparing and contrasting of two perspectives- that of the TRs and of the FDMs- and the development of a comprehensive coding schema or overall description of FDMs’ attitudes toward tissue donation.

For ease of coding, the first part of the FDM coding instrument was organized by attitude component (affect, behavior, and cognition) and further by positive and negative based on whether the codes (or attitude statements) expressed favorability towards tissue donation (which would be positive) or unfavorability towards tissue donation (which would be negative). After the three attitude components was a section for “other attitudes” or those that did not clearly fall into one of these categories, which was followed by a

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question on whether the FDM confused tissues with organs at any point during the request, and, if so, did the FDM associate tissues with organs in a positive, negative, or neither positive nor negative way. Other items were coded, such as counterarguments by TRs and whether the FDM mentioned TV, media, or movies, but were not able to be used for analyses due to there being little to no variability. Examples of the codes for each of the sections are provided in Table 3 along with the number of codes per question, excluding the codes for “other” where coders entered attitudes expressed that were different from the other attitude codes and were not included on the coding instrument. The FDM coding instrument is included in Appendix D.

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Table 3

Examples of Codes for Questions on the FDM Coding Instrument

Question ("Domain")	Example Codes ("Subdomains")	# of Codes Per Question
Affect	NOK is enthusiastic NOK feels good NOK does not want patient's body to be cut on NOK/family has been through enough already	16
Behavior	NOK had a discussion about donation with patient NOK told the patient in the past that donation was 'a good thing to do' NOK is NOT a registered donor NOK does NOT support patient's wishes	15
Cognitive	NOK believes it's the right thing to do It's better the tissue is used than unused There will be nothing left of patient NOK believes patient is still alive in some way	36
Other Attitudes	NOK wants to spare others the grief s/he is experiencing NOK feels that tissue donation is not necessary	4
Did FDM confuse tissues with organs?	Yes No No basis to tell	3
If s/he confused tissues with organs, how did s/he associate it?	NOK associated tissues with organs in a positive way NOK associated tissues with organs in a negative way NOK associated tissues with organs in neither a positive nor a negative way	3

Development of FDM coding manual. The FDM Coding Manual can be found in Appendix E. The purpose of the FDM Coding Manual is to provide a record of the coding instruction on and guidance to the coder. The manual included detailed explanations and definitions of the three attitude components and the codes listed on the instrument. Many of the codes included examples of quotes taken directly from the audiotapes. A few examples of codes and their definitions are provided in Table 4. The definitions for the codes came from looking across multiple cases [i.e., 10 in each FDM group] and creating a comprehensive, yet unified understanding of what the codes were trying to capture.

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Table 4

Examples of Codes and Their Definitions for FDM Audiofiles

Domain	Subdomain (Code)	Definition
Affective	NOK is grateful	<i>This code should be used when NOK expresses appreciation that this opportunity exists for the family, whether to help them cope or to help fulfill patient's wishes. Use this code if NOK expresses thanks to TR beyond the statement "thank you".</i>
	"Ick" factor	<i>The "ick" factor is a negative emotional reaction of disgust to the idea of tissue donation, in this case. Use this code if NOK responds to the request of tissue donation with disgust with a statement such as, "Ew!", "That's gross!", or says that anything regarding tissue donation makes him/her feel squeamish or uncomfortable.</i>
Behavioral	NOK had a discussion about donation with patient	<i>Use this code if NOK says that s/he talked to patient about tissue donation or patient's donation wishes. This code can also be used if NOK says that the patient told NOK what s/he wanted to do regarding donation.</i>
	NOK is NOT a registered donor	<i>Use this code when NOK specifically says that s/he is not a donor or does not intend to be.</i>
Cognitive	NOK believes tissue donation helps people	<i>Use this code if NOK says anything about tissues helping others or the use(s) of donation. For example, s/he may say, "if it helps others....". This code may be used if NOK discusses how tissues may improve the health of others or do "some good". This code should be used when the NOK mentions the beneficiary of donation. The NOK has to specifically mention a person or persons such as saying, "I think this decision will help others in need" as opposed to just saying "I feel like I made a good decision about donation". Use this code when NOK expresses that tissue donation is useful: "There's a great need for it," "I'm happy to give this gift," "Take whatever is useful."</i>
	Donation will alter patient's appearance	<i>Use this code when NOK says s/he thinks tissue donation will affect the patient's appearance or how the patient looks.</i>
Other	NOK wants to spare other families the grief s/he is experiencing	<i>Use this code when NOK states that they want to help someone else so that they don't have to go through what s/he is going through. NOK might say, "I don't wish this on anyone."</i>

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In addition, the manual contained a section of coding rules so that the coders would approach the coding task consistently. The research team consisted of 8 coders plus the researcher. The coding manual was the product of several iterations and resulted from an examination of the 30 test audiotapes and discussions at weekly group meetings with the coders. Definitions in the coding manual and coding rules were expanded, narrowed, or modified over the course of this process.

Recruitment of coders. Undergraduate students from the VCU Psychology Department were recruited. Students were recruited from the Psychology Department's annual recruiting event that students attend in April in order to gain research experience as part of an internship opportunity (PSY 494). Of the approximately 150 students who attended this event, 8 students were selected based on their qualifications and potential and commitment to do the necessary work.

Coders. Three of the students signed up for the summer 2012 semester and five students signed up for the fall 2012 semester. Altogether, the team of coders spent 855 hours training, coding, engaging in weekly meeting discussions, and entering data. The coders played an integral role in shaping the FDM Coding Instrument and FDM Coding Manual, including the reviewing of cases to make sure the instrument and coding manual accurately reflected the audiotapes. Once the coding schema and manual were completed, the coding team was ready to code.

Training coders. The researcher trained coders at the beginning of their internship. The training consisted of an introductory meeting where students were educated generally about qualitative research, the Tripartite Model of Attitude Structure, and the coding approach. The FDM Coding Manual was reviewed once together and

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students read the manual in detail before coding. Students read three important articles that provided some context about the study: 1) Breckler's 1984 article about the attitude components (Tripartite Model of Attitude Structure), 2) Siminoff's 2010 article about factors related to tissue donation consent, and 3) Siminoff's 2011 article about communication factors during the tissue donation request and their impact on consent. The researcher and coders jointly coded 2-3 cases together to demonstrate how to listen to the audiofiles, which were converted to digital files on the computer, and code a case using the instrument. Coders completed 5-10 practice cases depending on their speed of mastering the coding process.

Coding audiotapes for FDM attitudes. When students were ready to begin coding, they were assigned a caseload according to the number of hours they signed up for. Students attended hour-long weekly meetings every Thursday afternoon to discuss assigned cases and any coding questions they had. As qualitative coding is an iterative meaning-making process, they received continuous guidance throughout the coding process. The researcher worked closely with the coders during their weekly hours. While coders fulfilled their coding hours during the week independently, the weekly meetings provided an opportunity for all the coders to get together and generate clearer meaning for codes, clarify when to use certain codes, and discuss any discrepancies with their teammates so that all coders reached a consistent pattern of coding. Attitudes that did not "fit" into any of the codes in the instrument were placed into an "other" category. Any questions about coding that were not addressed in the codebook or that the coders could not come to agreement on were discussed with members of the dissertation committee. The coding manual was revised as needed.

Interrater reliability for coding of FDM audiorecordings. After all of the 240 FDM audiofiles were coded by the student coders, 24 (10%) of audiofiles were randomly selected and double coded by unique pairs of coders, such that all 8 coders were paired at least once with each other. The interrater reliability for the FDM audiofiles was 0.96.

Data management. Audiofiles from the TR interviews as well as the FDM audiofiles were stored as digital files on a HIPPA-compliant drive. All of the TR interviews and 30 of the FDM audiofile conversations were transcribed to aid in the development of codes and analysis. The coders were provided access to the HIPPA drive in order to listen to and code the audiofiles. After transcription, coding, and analysis, the audiorecordings were deleted from the drive.

Data entry. The data was entered into Qualtrics, a software program that is used to enter and export data (Qualtrics Labs Inc., 2012). This required creating two templates from the coding instruments, the TR Coding Instrument and the FDM Coding Instrument, into Qualtrics prior to data entry. The coding instruments are provided in Appendices B and D, respectively. These were used for the coding of all TR interviews and FDM audiofiles and then referred to when entering data into Qualtrics. Once all the cases were coded, the data was exported into SPSS for Windows v. 20.0 for data analysis (IBM SPSS Statistics, 2012).

Data entry reliability for TR interviews and FDM audiorecordings. Two (10%) and 24 (10%) cases were randomly selected for TR interviews and FDM audiofile data entry reliability, respectively. These cases were also randomly selected using the Research Randomizer internet tool. The TR interviews were double entered by one of the student coders in the internship and the FDM audiofiles were double entered by unique pairs of

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student coders, such that all 8 coders were paired at least once with each other. Data entry reliability was calculated by the percent agreement between the original data enterer and the reliability enterer to see how accurately coders entered the data from the paper coding instruments into Qualtrics. The data entry reliability for the TR interviews was 1.0 and for the FDM audiofiles was 0.98. All interrater reliability scores aligned well with reliabilities from past qualitative coding studies and positively exceeded the widely endorsed benchmark of 0.80 (Hartmann, 1977; House, House, & Campbell, 1981). All errors found in the original entries were corrected.

Summaries of attitudes. All attitude items (also known as subdomains or codes) for both TRs and FDMs are dichotomous ("0"= no attitude expressed and "1"=attitude expressed). Attitudes for both perspectives were described by domains and subdomains and included the total count and counts ("n") per domain. In order to compare and contrast the TR and FDM perspectives, a table or matrix with check marks next to the domains and subdomains present for each was generated. The congruence of domains and subdomains was described. In addition, rankings of the attitude domains, using the TR perspective as the reference point for interpretation, were provided as a means for displaying the relative importance of attitude domains to each perspective.

Data sources and data merge. Data cleaning was necessary in order to merge variables together from multiple sources. This required extracting the cases randomly selected for this study from the original datasets, the tissue study dataset (family interviews) and the SCCAP dataset from Siminoff's parent study and TR survey data, and merging this data with the FDM audiorecording coding primary data. These four datasets were merged together to create a single FDM dataset. The TR interview dataset was

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created separately. For the FDM dataset, missing values were imputed via multiple imputation (Rubin, 1987). Cases with more than 10% missing values were dropped from the analyses. Attitudes from the FDM dataset were ultimately collapsed in order to provide a clearer description of FDM attitudes. Categorical variables with little variability were ultimately collapsed into 2 or 3 categories.

FDM study variables and their sources. At first, the merged dataset consisted of approximately 2,000 variables, but was trimmed down significantly (over 75%) after looking at various characteristics of the data and through exploratory data analysis. The variables proposed for the study a priori were retained. Careful consideration of factors such as missing data, normality, variability, and meaning within the context of the current research influenced the retention or deletion of additional variables from the dataset. This was performed by observing their histograms and boxplots, the means and standard deviations, and checking for outliers. Asymmetry in distributions and extreme values were examined more closely and necessary transformations and deletions of outliers were made. Descriptions of the less defined variables, their measurement levels, item numbers, and sources (i.e., TR interviews, FDM expressed attitudes/FDM coding instrument, FDM interviews from Siminoff's tissue study, and SCCAP and TR surveys, also from Siminoff's tissue study) are discussed below and provided in Table 5.

Thought patient wanted to donate. The thought patient wanted to donate variable came from the tissue study family interviews and consisted of 3 categorical responses, which were ultimately collapsed into the categories wanted to donate and did not want to donate/unsure.

Time spent discussing tissue donation. Time spent discussing tissue donation was an open-ended question, which came from the tissue study's family interviews. This question specifically asked about FDMs' time spent discussing tissue donation with the Tissue Requester. Time spent discussing tissue donation ranged from 1-180 minutes.

Confusion of tissues with organs. The FDM confused tissues and organs variable was a question built into the FDM expressed attitudes coding instrument. Coders coded this item as "yes" if the FDM called tissues "organs" during the request or displayed confusion about the distinction between the two. Coders coded this item as "no" if such confusion was not indicated or there was no basis to tell. The FDM Coding Manual can be found in Appendix E, and explains an item description and the coding method in more detail.

Relational communication with TR. Item responses for the variable relational communication with TR were based on level of agreement on a 14 item 8-point Likert scale, which has been used in previous studies (Siminoff, Traino, and Gordon, 2010). The items were reverse coded for negatively worded items and summed together for a summative score, ranging from 37 to 98. Higher scores indicated more positive relational communication with the TR. Examples of items from this scale included, "S/he tried to control the interaction" and "S/he was willing to listen to me."

FDM affect. FDM affect came from the SCCAP and measured emotional content or FDMs' affect on an 8-point scale, from 0 to 7 with "0" representing an absence of the emotional content item, "1" representing a very low intensity of the emotion and "7" representing a very high intensity of the emotion. Coders from Siminoff's tissue study were trained over several months on coding these items and achieved an internal consistency reliability of 0.76 for the scale which included 8 items. Due to issues with variability and

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consistency of item types, only 6 of the 8 items from the original scale were retained for this study. Emotional content scales included involvement (from “detached” to “overly involved”), sincerity (from “insincere” to “very sincere”), dominance (from “passive” to “dominant”), friendliness (from “unfriendly” to “overly friendly”), animation (from “less animated” to “more animated”), and expressiveness (from “less expressive” to “more expressive”). FDM affect scores ranged from 0 to 41.

Initial receptivity to tissue donation request. This variable, initial receptivity to tissue donation request, was an item from the TR surveys completed by the TR staff who requested donation from the FDMs from Siminoff's tissue study. This item was a 7-point Likert scale, with “1” being “not all receptive” and “7” being “very receptive”.

General attitudes toward tissue donation. The general attitudes toward tissue donation variable was the sum score from a 14 item 5-point Likert scale, from strongly disagree to strongly agree, asked during the FDM interviews from Siminoff's study. Negatively worded items were reverse coded. The sum scores ranged from 26-66, with higher scores indicating more positive attitudes toward tissue donation. Examples of items from this scale were “It is acceptable for donated tissues to be made into medical products (e.g. screws made from bone for surgical use)” and “Tissue donation makes something positive come out of death”.

Level of surprise at request. This variable was a question asked during the FDM interviews from Siminoff's study. The FDM was asked to rate how surprised they were to be asked about tissue donation with “1” being “not at all surprised” and “7” being “very surprised”, unless the FDM raised the issue of tissue donation, in which case his/her response was recorded as “1 (not at all surprised)”.

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Table 5
FDM Study Variables and Their Sources

Variable	Item	Measurement Level			Item #	Source*
		Dichotomous	Categorical	Continuous		
Sociodemographics						
FDM relationship to patient	What is your relationship to your loved one?		✓		53	3
FDM's sex	What is your sex?	✓			54	3
FDM's ethnicity	Are you Hispanic or Latino/a?	✓			55	3
FDM's race	What is your race?		✓		56	3
FDM's age	What is your age?			✓	57	3
FDM education	What is the highest grade or level of education you've completed?			✓	58	3
FDM's marital status	What is your marital status?		✓		59	3
Health-related occupation	Is your occupation health or research-related?	✓			60	3
Religious affiliation	What is your religious affiliation?		✓		61	3
Income	Thinking back to when you made your donation decision, which of the following ranges best describes your household's total yearly income at that time?			✓	65	3
FDM Group						
FDM's initial reaction to request	What was your initial reaction to the request for tissue donation? Were you...		✓		10	3
			favorable, unsure, or unfavorable			
FDM Study Variables						
Willingness to donate own organs	Are you willing to donate your own organs?		✓		63	3
Willingness to donate own tissues	Are you willing to donate your own tissues?		✓		62	3
Donor card or license marked for donation	Do you have a donor card or your driver's license marked for donation?	✓			64	3
Thought patient wanted to donate	What did you think your loved one wanted? Do you think s/he would have.....		✓		27	3
			Wanted to donate,			

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		not wanted to donate, unsure of his/her wishes			
Thought patient wanted to donate	What did you think your loved one wanted? Do you think s/he would have.....	✓ Wanted to donate, not wanted to donate, unsure of his/her wishes	27	3	
Time spent discussing tissue donation	How much time did you spend talking about tissue donation when you were asked to donate? (total minutes)	✓	18b	3	
FDM confused tissues and organs	Did NOK confuse tissues with organs?	✓ Yes, No	10	2	
Relational communica- tion with TR	I am going to read you a series of statements about the conversation you had with the tissue requester. Please tell me whether you strongly disagree, moderately disagree, slightly disagree, slightly agree, moderately agree, or strongly agree with the statement.	✓	23a-n	3	
FDM affect	Rate the NOK's level of emotion [8-point scale].	✓	Ankec 04-09	4	
Initial receptivity to tissue request	How receptive was the NOK initially to the tissue donation request?	✓	3	5	
General attitudes toward tissue donation	I am going to read you a list of statements about tissue donation. Not all statements refer to current practices in tissue donation, but we would like your opinion nonetheless.	✓	39-52	3	
Level of surprise at request	Using a scale from one to seven with one being "not at all surprised" and seven being "very surprised", how surprised were you to be asked about tissue donation?	✓	9	3	

**1= TR interviews (primary data), 2=FDM expressed attitudes (primary data), 3=FDM interviews (secondary data), 4=SCCAP (secondary data), 5=TR surveys (secondary data)*

Describing the samples. The TR and FDM samples were both described demographically with counts and percentages for categorical variables and with means and standard deviations for continuous variables. The sociodemographic data reported on TRs was reported for those who provided basic information on themselves during the interviews. The sociodemographic data reported for the FDMs came from the secondary data provided by Siminoff's tissue study. Additional descriptive analyses of the FDM sample were conducted. Specifically, the three decision-maker groups (initially favorable, initially unsure, and initially unfavorable) were described by their relationships with study variables such as willingness to donate their own tissues and having their donor card marked for donation. Such relationships were examined using chi squared tests of independence for categorical dependent variables and student t-tests or ANOVAs for continuous dependent variables with 2 groups and more than two groups, respectively. Categorical variables with little to no variability of its values were collapsed into 2 or 3 categories. Significant findings at the alpha level of less than 0.05 and less than 0.001 were flagged with one and two asterisk marks, respectively. Where appropriate, post hoc analyses were conducted using Tukey's LSD to determine which FDM groups were significantly different from each other. All statistical analyses were performed using SPSS software (IBM SPSS Statistics, 2012).

Specific Aim 2: Assess the differences in attitude components between three groups of families (initially favorable, unsure, and unfavorable).

The coding of FDM audiorecordings performed in Specific Aim 1 was integral in accomplishing Specific Aim 2, which involved the statistical analyses of FDMs' attitudes.

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Bivariate analyses were first performed to assess relationships between attitude domains and FDM sociodemographic variables, FDM knowledge of patient's wishes, FDM groups, and other FDM characteristics. This was followed by multivariate analyses to assess differences between groups of FDMs in terms of their attitudes. The analyses conducted to accomplish Specific Aim 2 are discussed below.

Relationships between attitude domains and study variables. As the first study of its kind to analyze FDMs' expressed attitudes toward tissue donation, it was necessary to first explore what relationships were present between the study variables. A number of bivariate analyses were performed between attitude domains expressed by FDMs and FDM sociodemographics, FDM knowledge of patient's wishes, FDM initial response group, and other FDM characteristics. With attitudes expressed or not expressed in each domain as the independent variables, chi squared tests of independence were conducted for dependent categorical variables. Chi squared results were not reported for tests that had cells with expected counts of less than 5 as this violates the assumptions for the test. For continuous dependent variables, student's t-tests were performed. The non-parametric alternative, Mann-Whitney U tests, were performed simultaneously with the t-tests. The p-values for the Mann-Whitney U tests were reported if they were significant at the 0.05 level.

K-means cluster analysis. As a way to explore patterns of attitudes, specifically which FDMs clustered together based on their attitudes, a k-means cluster analysis was performed with Fisher's linear discriminant functions method. K-means cluster analysis was used on the attitude domains to evaluate the tenability of solutions varying the number of clusters from 2-8. For easier interpretation of the results, the attitude domains

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were dummy coded with “1” representing any attitudes expressed within that domain, and “0” representing no attitudes expressed in that domain. The distances between all the clusters, which demonstrate how dissimilar they are from each other (i.e. the larger the distance, the more dissimilarity between clusters), were reported. Generally, distances less than 3 are considered small, indicating that clusters are fairly similar (Aldenderfer & Blashfield, 1984).

Sum attitude component scores. A MANCOVA analysis was proposed, which would include 3 continuous outcome variables (attitude components) and compare if their means are different among the 3 groups after controlling for covariates. To derive continuous outcome variables, a factor analysis was proposed. Due to problems encountered with the observed variables having low item frequencies, showing little to no variance, a factor analysis was deemed inappropriate. Instead, the sum scores for the outcome variables were used as dependent variables in the originally proposed the MANCOVA analysis. Affective attitudes consisted of the sum of 9 affective codes/attitudes; behavioral attitudes consisted of the sum of 12 behavioral codes/attitudes; and cognitive attitudes consisted of the sum of 13 cognitive codes/attitudes. Higher sum scores indicated more expressed attitudes. The sum scores for FDMs' affective attitudes ranged from 0-4; FDMs' behavioral attitudes ranged from 0-3; and FDMs' cognitive attitudes ranged from 0-5 attitudes.

Multivariate analyses. Before conducting the MANCOVA, the data was checked for normality, linearity, univariate and multivariate outliers, homogeneity of variance-covariance matrices, and reliable measure of the covariates. A one-way MANCOVA was conducted to test the mean differences in affective, behavioral, an attitude components

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among three types of decision-maker groups. The independent variable was FDM initial response group (initially favorable, unsure, and unfavorable). The dependent variables were the three attitude sum scores (affective, behavioral, and cognitive attitudes).

Covariates that have been found to significantly contribute to attitudes in past research were included in the analysis. The covariates included: 1) race, 2) education, 3) religion, 4) relationship to patient, and 5) thought patient wanted to donate. As the covariates in the MANCOVAs did not play a significant role in explaining the variance in the combined dependent variables, a MANOVA (without the covariates) was conducted, and the results from this analysis were reported.

In addition, a second MANCOVA was conducted, which included significant study variables identified from the bivariate analyses. Each of the significant study variables was entered independently of each other as covariates in the MANCOVA model. The partial eta-squared values for each of these covariates was recorded and sorted into descending order. The top 3 study variables, those with the highest partial eta-squared values, were selected for inclusion in the model as they explained the most of the variance in the outcome variables. A MANCOVA using the 3 study variables as covariates rendered only 2 as significant. Thus, these 2 study variables, 1) confused organs with tissues and 2) time spent discussing tissue donation, were the covariates used in the second MANCOVA.

The significant multivariate effects for each of these analyses were reported. If significant effects were found, the dependent variables were looked at independently to see if there were any between-subjects effects. Significant differences were reported using the Bonferroni adjusted p-value. Tukey's HSD test was applied in post hoc analyses designed to assess where the group differences were (Tukey, 1991). Significant mean differences

between groups and their confidence intervals were reported. All analyses were computed using SPSS version 20 statistical software (IBM SPSS, 2012).

Additional analyses. In order to know “...what specific variables best account for these differences” (Tinsley and Brown, 2000, p. 210), additional analyses were needed. As such, two discriminant function analyses were performed. The first discriminant function analysis included the same variables as the MANOVA, but the three sum score attitude components were the predictor variables and FDM initial response groups were the dependent variables. This analogous statistical technique added robustness and served as a method of triangulating the data findings from the MANOVA. In order to see which specific attitudes discriminated FDM groups beyond the three components, a second discriminant function analysis was performed. In the second discriminant analysis, the sum scores of the 14 attitude domains were the predictor variables and FDM initial response groups were the dependent variables. The structure matrices and predicted classifications from these analyses were reported.

Specific Aim 3: Develop a suggestion for an educational intervention to change the public's understanding of and attitudes toward tissue donation.

Specific Aim 3 builds on the results from Specific Aims 1 and 2. In addition, TRs' perceptions of factors contributing to FDMs' attitudes and their thoughts on messages to incorporate into an educational intervention, collected during the TR interviews, were integrated to accomplish Specific Aim 3: to develop a suggestion for an educational intervention on tissue donation.

TRs' perceptions of influences on FDMs' attitudes. TRs' responses to additional questions from the TR Interview Guide were compiled and reported in the results for Specific Aim 3. The questions pertaining to additional influences on FDMs' attitudes from the TR Interview Guide were Question 1, "In the course of speaking with families, you must hear many different things about tissue donation. Could you tell me how much or little knowledge people have about tissue donation?" and Question 3, "Now I'd like you to focus on some of the misconceptions you hear. What kinds of misconceptions are most common? How do you overcome these? Do these strategies work? (PROBE: Do their attitudes change when you employ these strategies? Do they still hold on to those beliefs?)" TRs' perceptions of influences on FDMs' attitudes were also drawn from tangential responses to other questions throughout the interviews. The specific topics reported in this section from the TR perspective were FDMs' knowledge about tissue donation, FDMs confusion between tissues and organs, spillover attitudes, and counterarguments used to overcome FDMs' misconceptions. The term spillover is used to refer to attitudes toward tissue donation that have carried over from attitudes toward organ donation.

TRs' thoughts for an educational intervention. During the interviews, TRs also provided their insights and thoughts on a potential educational intervention for tissue donation based on their experience speaking with families. Specific questions addressing this topic were Questions 9-11 on the TR Interview Guide: Q9-Do you see much public education on tissue donation? (PROBE: What do you see?); Q10-What do you think would be the most important messages to include in an educational intervention about tissue donation for the general public? Is there any particular group you would target? Why?; and, Q11-Do you think educating the public about tissue donation would help to increase

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consent rates? Why or why not? As with the data on TRs' perceptions of influences on FDMs' attitudes discussed above, these were open-ended questions and the results were the product of qualitative coding of the TRs' responses. ATLAS.ti was used to assist with the management of interview transcripts and organization of codes, and SPSS was used to analyze frequencies and other descriptive characteristics of the TR data. Counts and percentages as well as means and standard deviations were reported to quantify the data as appropriate.

Presentation to TRs. With approval from the Director of Donor Services at LifeNet Health, the preliminary results of this study were presented to the TRs at a staff meeting in February 2013. After the presentation, the TRs were engaged in an open forum to discuss their thoughts on the findings thus far and obtain additional feedback for an educational intervention. All TRs consented to the forum being audiorecorded. The conversation was transcribed by qualitative content analysis of the transcript and reported thematically.

Suggestions for an educational intervention. Drawing on the TRs' perspective from the earlier interviews and the findings of the study, the pros and cons of the TRs' suggestions for an educational intervention were discussed. Finally, an argument for the best educational intervention out of the suggestions was provided.

Chapter V. Results

The results section is organized by Specific Aim. Specific Aim 1 examines tissue donation attitudes and is presented as how these are characterized from the perspectives of the TRs' and the FDMs'. Specific Aim 2 is an examination of the associations between the independent variables and the differences in attitudes of three a priori groups of FDMs. These groups are characterized by their initial response to the donation request- favorable, unsure, and unfavorable. Specific Aim 3 is a consideration of what the data suggests in terms of the design of an educational intervention to educate the public about tissue donation.

Specific Aim 1: Understand attitude formation and how attitudes toward tissue donation were developed

I. (TRs) Perceptions of FDMs' Attitudes

First, a brief description of the TR sample is provided, which is followed by a presentation of the domains and subdomains of TRs' perceptions of FDMs' attitudes.

TR sample. The Tissue Requester (TR) sample was comprised of 14 individuals of whom 71.4% ($n=10$) were female and 85.5% ($n=12$) were Caucasian. TRs had a mean age of 37.9 years ($SD=8.6$) (see Table 6).

Table 6
TR Sociodemographics

Sociodemographic	<i>N</i> =14 <i>n</i> (%)
Sex	
Male	4 (28.6)
Female	10 (71.4)
Ethnicity	
Hispanic	2 (14.3)
Non-Hispanic	12 (85.7)
Race	
Caucasian	12 (85.7)
African American	2 (14.3)
Age*	37.9 (8.6)

**Note. Values are mean and standard deviation and is based on 8 TRs who provided this information*

Domains and subdomains of TRs' perceptions of FDMs' attitudes. TRs were interviewed to investigate their perceptions of FDMs' attitudes. TRs provided their thoughts and insights about FDMs' attitudes based on their extensive past experiences of making telephonic requests for tissue donation with the families of deceased patients. The TR interview was designed to prompt TRs to re-examine their conversations with FDMs and reflect on and assess FDMs' attitudes toward tissue donation.

As hypothesized, the three components of attitudes, behavioral, affective, and cognitive, emerged after coding the interviews. TRs answered questions that referenced these three components. Each attitudinal component was found to contain different domains and subdomains, which are organized in Table 7 from most to least endorsed attitudes by TRs. Each of these domains and their subdomains are described below and labeled with a letter A, B, or C representing the (A)ffective, (B)ehavioral, and (C)ognitive components respectively. In addition, each is numbered from 1-6, to indicate the order

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from most frequently referenced (1) to least frequently referenced (6). At the end of this section, Table 7 provides a summary of the domains and subdomains that mapped onto the three attitude components for FDMs' attitudes. It is important to keep in mind that the following domains and subdomains represent the TRs' perceptions of families' attitudes toward tissue donation.

Cognitive component. The cognitive component was the most frequently endorsed attitudinal component, with a total of 75 endorsements. There were 6 major domains in the cognitive component category: 1) distrust of medical/tissue industry, 2) negative physical changes, 3) false beliefs regarding eligibility, 4) donation is valuable, 5) religious beliefs, and 6) donation process/timing.

(C1) Distrust of medical/tissue industry. The domain, distrust of medical/tissue industry, emerged from the interviews with TRs and refers to FDMs' misconceptions about the medical field or tissue donation industry. At the heart of the attitudes in this domain is the belief that medical professionals (ie. doctors, nurses, tissue procurement team) cannot be trusted to do the right thing, whether it be treating the patient with respect or putting the life of the patient as a first priority. The subdomains include FDMs belief that the patient's body parts will be taken or stolen ($n=6$), not enough medical attention will be given to the patient ($n=4$), the tissue donation industry is sinister and manipulative ($n=3$), tissues will be wasted (i.e., 'thrown away') ($n=2$), the patient's body will not be treated with respect ($n=1$), and rich people are given preference for transplantation ($n=1$).

(C2) Negative physical changes. Another domain frequently endorsed was negative physical changes. This domain includes disagreeable attitudes regarding how donation will affect the integrity or appearance of the patient's body. The subdomains derived from the

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TR perspective include FDMs' belief that donation will alter patient's appearance ($n=11$), FDMs belief/want the patient to go out of the world the way s/he came into it ($n=3$), and FDMs' belief the patient will not feel the same ($n=2$). The first subdomain regarding appearance includes beliefs about the patient being disfigured or mutilated, torn apart, there being nothing left of the patient, and the patient being "just flab" after donation. The second subdomain includes the desire for the patient's body to remain whole after death and is sometimes associated with religious preferences. The third subdomain denotes how the patient might literally feel after tissues are procured (e.g. feeling hollow or full, warm or cold).

(C3) False beliefs regarding eligibility. This domain refers to FDMs' incorrect assessment of the patient's ineligibility to donate. The subdomains include FDMs' belief that the patient's tissues are not suitable for donation ($n=7$), FDMs' belief that tissue donation is not possible because the patient is dead ($n=4$), and FDMs' belief that tissue donation is only possible if the patient is being cremated ($n=3$). The first subdomain regarding suitability of the patient's tissues include a belief that the patient is too old or has had too many medical conditions or illnesses to donate. The second subdomain derives from the FDMs' lack of understanding about tissue donation and confusion with organ donation. The third subdomain reflects similar lack of knowledge about the specifics for tissue donation.

(C4) Donation is valuable. This domain describes FDMs' attitudes concerning the utility. The subdomains include FDMs' belief that tissue donation helps people/saves lives ($n=8$), that using the tissue is better than wasting it ($n=2$), and simply that it is 'the right thing to do' ($n=2$).

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(C5) Religious beliefs. This domain encompasses beliefs about life after death or the patient's 'spirit'. The subdomains include FDMs' belief that it is against the patient's (or their own) religion ($n=5$) and that the patient is still alive in some way ($n=4$).

(C6) Donation process/timing. This domain includes FDMs' attitudes regarding the logistics of tissue donation and how donation fits in with the other responsibilities surrounding the death of a loved one. The subdomains are FDMs' belief that tissue donation will delay the funeral ($n=4$), incorrectly inferring that they would have to return to the hospital to donate the patient's tissues ($n=2$), concern of not being able to spend time with the patient before the donation ($n=1$). Regarding the subdomain about going to the hospital, FDMs hold this belief when they are not aware that the consent for tissue donation takes place over the telephone.

Affective component. Of the three attitude components, the affective component was the second most frequently endorsed, with 54 total endorsements. There were 3 major domains or themes in the affective category: 1) aversion to changing the appearance of the body after death, 2) positive emotions invoked by donation, 3) and negative emotions.

(A1) Aversion to changing the appearance of the patient's body after death. This domain was the most frequently discussed. From most to least endorsed, the subdomains include the notion that the patient has already been through enough ($n=13$), not wanting the patient's body to be touched or "cut on" ($n=9$), and wanting to remember the patient the way s/he was ($n=1$).

(A2) Donation invokes positive emotion. This domain encompasses FDMs' positive emotional attitudes toward tissue donation. While often combined with other attitudes,

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TRs described donation as involving positive emotion such as altruism, a reconciling the grief over the death versus their satisfaction with helping others through donation, or a sense of relief or peace with their thoughts toward tissue donation. Although TRs expressed that families share the sentiment of feeling glad to donate, two distinct subdomains were denoted. Subdomains include FDMs feeling good about tissue donation ($n=8$) and FDMs feeling enthusiastic about tissue donation ($n=2$). FDMs feeling enthusiastic about tissue donation involves FDMs expressing eagerness to help others through donation; whereas, FDMs feeling good about tissue donation involves FDMs feeling comforted by donation and feeling thankful for something positive to come out of a tragic situation.

(A3) Donation invokes negative emotion. This domain embodies the negative emotions FDMs feel about tissue donation. TRs described negative emotions as a visceral reaction to the thought of various aspects of donation or the process. Specifically, the subdomains include FDMs feeling tissue donation is barbaric ($n=8$) and FDMs feeling guilty about making a decision ($n=2$). The word 'barbaric' was used interchangeably with words like offensive and disgusting.

Behavioral component. The behavioral component was the least frequently endorsed of the three attitude components, totaling 33 endorsements. There were 4 domains in the behavioral attitudes category: 1) patient's wishes, 2) anti-donation behaviors, 3) pro-donation behaviors, and 4) direct past experience with donation.

(B1) Patient's wishes. The domain with the highest endorsement in the behavioral attitudes category is patient's wishes. This domain represents FDMs who perform behaviors or actions on the basis of what they understood as the patient's donation

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preferences, whether for or against tissue donation. More specifically, the subdomains include FDMs support of patient's donation wishes ($n= 10$), FDMs non- support of patient's donation wishes ($n=4$), and FDMs had a discussion about donation with patient ($n=3$).

(B2) Anti-donation behaviors. The subdomains include negative discussions about donation with other family members and friends ($n=5$) and FDMs are not registered donors ($n=1$).

(B3) Pro-donation behaviors. The subdomains include FDMs are registered donors ($n=2$), FDMs had positive discussions about donation with other family members and friends ($n=2$), and FDMs told the patient in the past that donation was 'a good thing to do' ($n=1$).

(B4) Direct past experience with donation. This domain includes FDMs involvement or past experiences with donating either their own or a family member's tissues or organs or having been a recipient of donated tissues or organs. The subdomains include FDMs were involved with donation in some way ($n=3$) and having donated before ($n=2$).

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Table 7

Domains and Subdomains Derived from Tissue Requester Interviews

Affective Component	n (%)	Behavioral Component	n (%)	Cognitive Component	n (%)
(A1) Aversion to changing body after death		(B1) Patient's wishes		(C1) Distrust of medical/tissue industry	
FDMs feel the patient has been through enough already. 13 (92.9)		FDMs support patient's wishes. 10 (71.4)		FDMs believe patient's body parts will be taken/stolen. 6 (42.9)	
FDMs do not want patient's body to be touched/cut on. 9 (64.3)		FDMs do NOT support patient's wishes. 4 (28.6)		FDMs believe not enough medical attention will be given to patient. 4 (28.6)	
FDMs want to remember the patient the way s/he was. 1 (7.1)		FDMs had a discussion about donation with patient. 3 (21.4)		FDMs believe tissue donation industry is sinister and manipulative. 3 (21.4)	
(A2) Donation invokes positive emotion		(B2) Anti-donation behaviors		FDMs believe tissues will be wasted. 2 (14.3)	
FDMs feel good about tissue donation. 8 (57.1)		FDMs have discussed donation with family/friends/others (and it was negative) 5 (35.7)		FDMs believe patient's body will not be treated with respect. 1 (7.1)	
FDMs are enthusiastic about tissue donation. 2 (14.3)		FDMs are not registered donors. 1 (7.1)		FDMs believe rich people are given preference for transplantation. 1 (7.1)	
(A3) Donation invokes negative emotion		(B3) Pro-donation behaviors		(C2) Negative physical changes	
FDMs feel tissue donation is barbaric. 8 (57.1)		FDMs are registered donors. 2 (14.3)		FDMs believe donation will alter patient's appearance. 11 (78.6)	
FDMs feel guilty about making a decision. 2 (14.3)		FDMs have discussed donation with family/friends/others (and it was positive). 2 (14.3)		FDMs believe/want the patient to go out of the world the way s/he came into it. 3 (21.4)	
		FDMs told the patient in the past that donation was 'a good thing to do'. 1 (7.1)		FDMs believe patient will not feel the same. 2 (14.3)	
		(B4) Direct past experience with donation		(C3) False beliefs regarding eligibility	
		FDMs are involved with donation in some way. 3 (21.4)		FDMs believe patient's tissues are not suitable for donation. 7 (50.0)	
		FDMs have donated before. 2 (14.3)		FDMs believe tissue donation is not possible because patient is dead. 4 (28.6)	
				FDMs believe tissue donation is only possible with cremation. 3 (21.4)	
				(C4) Donation is valuable	
				FDMs believe tissue donation helps people/saves lives. 8 (57.1)	
				FDMs believe using the tissue is better than wasting it. 2 (14.3)	
				FDMs believe it is 'the right thing to do.' 2 (14.3)	
				(C5) Religious beliefs	
				FDMs think it's against patient's/their religion. 5 (35.7)	
				FDMs believe patient is still alive in some way. 4 (28.6)	
				(C6) Donation process/timing	
				FDMs believe tissue donation will delay the funeral. 4 (28.6)	

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			FDMs think they have to return to the hospital to donate patient's tissues. 2 (14.3)
			FDM's concern of not being able to spend time with the patient before the donation again. 1 (7.1)
Total	54	33	75

II. FDMs' Expressed Attitudes

First, the FDM sample is described including a brief examination of the association between FDM characteristics and initial willingness to donate. Relationships were identified using chi squared tests of independence for categorical variables and one-way ANOVAs for continuous variables, and post hoc analyses using Tukey's LSD were performed to determine where differences lie. The next section describes the domains and subdomains of FDMs' expressed attitudes toward tissue donation.

FDM sample. FDMs were primarily female (74.6%), Caucasian (80.0%), Protestant (58.0%) and spouses of the patient (41.7%). About 75% of FDMs in this sample were between the ages of 36 and 65; the mean age was 51.59 years ($SD=13.75$). The majority of FDMs were either widowed (45.8%) or married (35.4%) and had an average education of 13.70 years ($SD=2.33$). In addition, 55.5% of FDMs earned an annual household income of \$49,999 or less, 24.2% earned between \$50,000 and \$89,999, 12.1% earned \$90,000+, and 2.1% did not know their household annual income. The plurality of FDMs earned an annual household income of \$44,500. Thirty-one (12.9%) FDMs had a health-related occupation. One hundred and eleven (46.3%) FDMs said they had their driver's license or donor card marked while 129 (53.8%) FDMs said they did not. The data are presented in Table 8.

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FDMs' willingness to donate their own organs resembles FDMs' willingness to donate their own tissues. Specifically, 170 (70.8%) FDMs said they were willing to donate their own organs and 167 (69.6%) FDMs said they were willing to donate their own tissues. Seventy (29.2%) FDMs said they were not willing or not sure if they wanted to donate their own organs and 73 (30.5%) said they were not willing or not sure if they wanted to donate their own tissues.

The plurality of FDMs in each response group (favorable, unsure, and unfavorable) was similar in sociodemographic characteristics, except in terms of whether they had their donor card or license marked for donation and their relationship to the patient. FDMs who were initially favorable towards tissue donation were mostly female (68.8%), Caucasian (90.0%), not married/widowed (65.0%), the spouse of the patient (46.2%), Protestant (59.5%), and had their donor card or their license marked for donation (71.3%). On average, they were 52.77 years old, had 14.10 years of education, and earned an annual household income of \$49,700. FDMs who were initially unsure about tissue donation were mostly female (80.0), Caucasian (83.8%), not married/widowed (62.5%), had a relationship to the patient other than a spouse or parent (43.8%), Protestant (53.8%), and did not have a donor card or license marked for donation (60.0%). On average, they were 48.45 years old, had 13.68 years of education, and earned an annual household income of \$45,100. Finally, FDMs who were initially unfavorable towards tissue donation were mostly female (75.0%), Caucasian (66.5%), not married/widowed (66.2%), had a relationship to the patient other than a spouse or parent (47.5%), Protestant (60.8%), and did not have a donor card or license marked for donation (72.5%). On average, they were

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53.54 years old, had 13.33 years of education, and earned an annual household income of \$38,700.

FDMs who were initially unfavorable towards tissue donation were more likely than those FDMs who were initially unsure to be older (53.54 vs. 48.45 years, $F(2, 237)=3.25$, $p=0.041$). They were also more likely than those who were unsure or favorable to be non-white (33.5% vs. 26.5%, $\chi^2(2, N=240)=14.87$, $p=0.001$). FDMs who were favorable were more likely than those who were unsure or unfavorable to have a donor card (71.3% vs. 67.5%, $\chi^2(2, N=240)=32.68$, $p\leq 0.001$), believe that their loved one wanted to donate tissues (87.5% vs. 53.8% and 25.0%, respectively; $\chi^2(2, N=240)=63.73$, $p\leq 0.001$) and more likely to be willing to donate their own organs (92.5% vs. 71.3%, $\chi^2(2, N=240)=37.44$, $p\leq 0.001$) and tissues (93.8% vs. 70.0%, $\chi^2(2, N=240)=44.93$, $p\leq 0.001$).

FDMs that were initially favorable were more likely to have more positive attitudes toward tissue donation generally than FDMs that were initially unsure as well as FDMs that were initially unfavorable ($M=52.70$ vs. 48.09 vs. 45.28; $F(2, 237)=23.59$, $p\leq 0.001$), better relational communication with TRs ($M=81.19$ vs. 73.85 vs. 65.52; $F(2, 237)=24.18$, $p\leq 0.001$), greater receptivity to tissue donation initially ($M=6.33$ vs. 4.68 vs. 3.28; $F(2, 237)=61.77$; $p\leq 0.001$), and a lower level of surprise by the request ($M=3.08$ vs. 4.43 vs. 5.47; $F(2, 237)=20.45$, $p\leq 0.001$). FDMs that were initially favorable and unsure were more likely to have spent more time discussing tissue donation with the TR than those that were initially unfavorable ($M=24.92$ and 20.57 vs. 6.55; $F(2, 237)=18.29$, $p\leq 0.001$).

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Table 8

FDM Initial Response to the Donor Request and Association with Independent Variables

	Total FDMs <i>N</i> =240 <i>n</i> (%)	Initially Favorable FDMs <i>N</i> =80 <i>n</i> (%)	Initially Unsure FDMs <i>N</i> =80 <i>n</i> (%)	Initially Unfavorable FDMs <i>N</i> =80 <i>n</i> (%)	χ^2	<i>p</i>
Sex						
Male	61 (25.4)	25 (31.3)	16 (20.0)	20 (25.0)	2.68	0.262
Female	179 (74.6)	55 (68.8)	64 (80.0)	60 (75.0)		
Ethnicity†						
Hispanic	8 (3.3)	0 (0.0)	2 (2.5)	6 (7.6)	---	---
Non-Hispanic	232 (96.7)	80 (100.0)	78 (97.5)	74 (92.4)		
Race**						
Caucasian	192.2 (80.0)	72 (90.0)	67 (83.8)	53.2 (66.5)	14.87	0.001
Non-Caucasian	47.8 (20.0)	8 (10.1)	13 (16.4)	26.8 (33.5)		
Marital Status						
Married	85 (35.4)	28 (35.0)	30 (37.5)	27 (33.8)	0.255	0.88
Not married/widowed	155 (64.6)	52 (65.0)	50 (62.5)	53 (66.2)		
Relationship to patient						
Spouse	100 (41.7)	37 (46.2)	29 (36.2)	34 (42.5)	4.29	0.368
Parent	35 (14.6)	11 (13.8)	16 (20.0)	8 (10.0)		
Other	105 (43.8)	32 (40.0)	35 (43.8)	38 (47.5)		
Religious Affiliation						
Protestant	139.4 (58.0)	47.8 (59.8)	43 (53.8)	48.6 (60.8)	3.78	0.437
Catholic	46.6 (19.4)	11 (13.7)	19.4 (24.2)	16.2 (20.2)		
Other	54 (22.5)	21.2 (26.5)	17.6 (22.0)	15.2 (19.0)		
Health-related occupation						
Yes	31 (12.9)	8 (10.0)	13 (16.3)	10 (12.5)	1.41	0.495
No	209 (87.1)	72 (90.0)	67 (83.8)	70 (87.5)		
Willing to donate own organs**						
Yes	169.8 (70.8)	74 (92.5)	57 (71.3)	38.8 (48.5)	37.44	≤0.001
No/Don't know	70.2 (29.2)	6 (7.6)	23 (28.8)	41.2 (51.5)		
Willing to donate own tissues**						
Yes	167 (69.6)	75 (93.8)	56 (70.0)	36 (45.0)	44.93	≤0.001
No/Don't know	73 (30.5)	5 (6.3)	24 (30.0)	44 (55.0)		
Donor card or license marked**						
Yes	111 (46.3)	57 (71.3)	32 (40.0)	22 (27.5)	32.68	≤0.001
No	129 (53.8)	23 (28.8)	48 (60.0)	58 (72.5)		
Thought patient wanted to donate tissues**						
Wanted to donate	133 (55.4)	70 (87.5)	43 (53.8)	20 (25.0)	63.73	≤0.001
Not wanted to donate	44 (18.3)	3 (3.7)	15 (18.7)	26 (32.5)		
Unsure of patient's Wishes	63 (26.2)	7 (8.8)	22 (27.5)	34 (42.5)		
Confused tissues with organs						
Yes	27 (11.2)	9 (11.2)	13 (16.2)	5 (6.2)	4.00	0.135
No	213 (88.8)	71 (88.8)	67 (83.8)	75 (93.8)		
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>F</i>	<i>p</i>
Age* (in years)	51.59 (13.75)	52.77 (14.37)	48.45 (14.05)	53.54 (12.36)	3.25	0.041
Education (in years)	13.70 (2.33)	14.10 (2.4)	13.68 (2.09)	13.33 (2.45)	2.27	0.11
Income††	5.45 (3.16)	5.97 (3.16)	5.51 (3.10)	4.87 (3.17)	2.53	0.10

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General attitudes toward tissue donation**	48.69 (7.53)	52.70 (5.56)	48.09 (7.43)	45.28 (7.54)	23.59	≤0.001
Affect	21.79 (8.49)	22.55 (7.99)	21.68 (8.53)	21.15 (8.95)	0.562	0.573
Relational communication with TR**	73.52 (15.61)	81.19 (12.58)	73.85 (15.17)	65.52 (14.96)	24.18	≤0.001
Initial receptivity to tissue donation request**	4.76 (2.13)	6.33 (1.27)	4.68 (2.02)	3.28 (1.84)	61.77	≤0.001
Level of surprise by request**	4.33 (2.56)	3.08 (2.39)	4.43 (2.46)	5.47 (2.25)	20.45	≤0.001
Time spent discussing tissue donation with TR (in minutes)**	17.35 (21.65)	24.92 (17.77)	20.57 (27.33)	6.55 (12.48)	18.29	≤0.001

*p≤0.05; **p≤0.001

†Chi-squared test could not be performed because one or more cells have an expected count(s) of less than 5.

††Values for the income variable range from 1-11, where 1=under 10k, 2=10k-19,999, 3=20k-29,999....11=100k+

Domains and subdomains of FDMs' attitudes. The domains and subdomains for FDMs' expressed attitudes, including their respective counts and percentages discussed here in detail and summarized in Table 9.

Behavioral component. The behavioral component was the most frequently endorsed attitude component, with 212 total endorsements. There were 4 major domains or themes in the behavioral category as described below.

(B1) Patient's wishes. This is the most frequently endorsed domain. This domain includes attitudes about the patient's preferences for donation as well as statements that they have always supported the patient's endeavors or wishes and want to follow the patient's wishes regarding donation as well as not supporting the patient's wishes. Three subdomains were identified: FDM supports patient's wishes ($n=70$), FDM had a discussion about donation with the patient ($n=24$), and FDM does NOT support patient's wishes ($n=10$).

(B2) Pro-donation behaviors. The second most frequently endorsed domain is pro-donation behaviors. This domain refers to FDMs' attitudes that express explicit support for

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tissue donation. Four subdomains were identified: FDM has had positive discussions about donation with other family members ($n=39$), FDM is a registered donor ($n=18$), FDM has had positive discussions about donation with others (i.e., friends, strangers) ($n=5$), and FDMs told the patient in the past that donation was 'a good thing to do' ($n=2$).

(B3) Anti-donation behaviors. This domain refers to FDMs' attitudes that are against tissue donation. Three subdomains were identified: FDM has had negative discussions about donation with other family members ($n=39$), FDM has had negative discussions about donation with others ($n=6$), and FDM is not a registered donor ($n=1$).

(B4) Direct past experience with donation. This domain includes FDMs' involvement with tissue donation in the past. The two subdomains include, FDM has donated before ($n=1$) and FDM has been involved with donation in some way ($n=7$); both refer to direct past experience with donation. The latter includes experiences such as, being a recipient of tissue donation or having a friend who has donated their own or a family member's tissues before. The subdomain, FDM has been involved with donation in some way, also includes community engagement with or prior work involving tissue donation.

Cognitive component. The cognitive component was the second most frequently endorsed attitude component, with 181 total endorsements. There were 6 major domains or themes in the cognitive category as described below.

(C1) Donation is valuable. This was the most frequently endorsed cognitive domain. It includes statements about the commendable nature of tissue donation and why donating tissues is a good idea. Three subdomains were identified: FDM believes tissue donation helps people/saves lives ($n=36$), FDM believes it is 'the right thing to do' ($n=31$), and FDM believes using the tissue is better than wasting it ($n=18$).

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(C2) False beliefs regarding eligibility. This is the second most frequently endorsed domain. This domain includes statements such as, the patient is too old to donate, the patient has too many medical conditions/diseases, the tissues will not be of any use to anyone, and a previous injury prevents the patient from donating. Two subdomains were identified: FDM believes patient's tissues are not suitable for donation ($n=45$) and FDM believes tissue donation is only possible with cremation ($n=1$).

(C3) Curiosity about negative physical changes. This domain refers to concern about damaging changes to the patient's body. Two subdomains were identified: FDM believes donation will alter the patient's appearance ($n=27$) and FDM wants the patient to go out of the world the way s/he came into it (i.e., 'whole') ($n=2$).

(C4) Money. This domain includes statements about the cost of donation as well as concerns about the profit-making facets of the tissue donation industry. In addition, this domain refers to statements about the family having to pay for the costs of transporting the patient's body from the hospital or place of tissue procurement to the funeral home. Two subdomains were identified: it will cost money to donate tissues ($n=8$) and the tissue donation industry is all profit-driven ($n=1$).

(C5) Donation process/timing. This domain includes the logistical aspects of tissue donation. Two subdomains were identified: FDMs belief that tissue donation will delay the funeral ($n=6$) and FDM's concern of not being able to spend time with the patient before the donation ($n=1$).

(C6) Religious beliefs. The least endorsed domain was religious beliefs. This domain encompasses beliefs about the patient needing all his/her parts in order to go to heaven, the eyes being the windows of the soul, and necessity to remain intact in order to be

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reincarnated. Two subdomains were identified: FDM thinks it is against the patient's religion or FDM's religion ($n=4$) and FDM believes the patient is still alive in some way ($n=1$).

Affective component. Of the three attitude components, the affective component was the least frequently endorsed, with 155 total endorsements. There were 4 major domains or themes in the affective attitudes category as described below.

(A1) Donation invokes positive emotion. This is the most frequently endorsed affective domain. This domain includes FDMs' expressed positive emotions towards donation. Three subdomains were identified: FDM feels good about tissue donation ($n=65$), FDM feels enthusiastic about tissue donation ($n=4$), and FDM feels grateful ($n=4$). FDMs who felt enthusiastic made statements such as, "This is a wonderful opportunity" or "This is so great, more people should do it." The intensity of positive emotion towards tissue donation is greater in the "FDM feels enthusiastic" subdomain than in the "FDM feels good" subdomain. The "FDM feels good" subdomain includes positive assertions about the donation process/tissue request as a whole. FDMs need not agree with all aspects of tissue donation or even consent to donate, but, at some point, they expressed positive emotion (i.e., the NOK says, "I feel a little better now that I made this decision"). Moreover, this subdomain includes FDMs' expression of a sense of relief about their decision.

(A2) Aversion to changing the body after death. The second most frequently endorsed domain was aversion to changing the body after death. This refers to FDMs' negative emotional reactions to altering the patient's appearance. Two subdomains were identified: FDM feels the patient has been through enough already ($n=35$) and FDM does not want patient's body to be touched/cut on ($n=7$). The first subdomain entails

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statements such as “the patient has suffered enough” and not wanting the patient to experience any more pain. FDMs sometimes stated that their loved ones had a chronic disease and they wanted them to rest. The second subdomain includes statements such as “I don’t want them doing anything to his body” and “I don’t want the body being messed with.”

(A3) Donation invokes negative emotion. This domain refers to FDMs’ negative emotions toward tissue donation. Two subdomains were identified: FDM feels guilty about making a decision ($n=26$) and FDM feels tissue donation is barbaric ($n=6$). The first subdomain denotes an expression of guilt about making a decision. The feeling of guilt stems from not wanting to upset other members of the family but still wanting or needing to make the decision. FDMs may also state that they do not want to make the decision on their own and they need the advice/input of other family members and/or friends. Further, this subdomain includes hesitation or a feeling of regret beyond simply wanting to have an educated discussion about the topic with the rest of the family, friends, or others. Another example of this subdomain is when FDMs feel conflicted as they do not support donation but their loved ones expressed wishes in favor of donation. The second subdomain encompasses attitudes of disgust towards tissue donation. FDMs may say they are offended by the request or the idea of donating.

(A4) Conditional donation. This domain describes attitudes that are “deal breakers” for the FDMs. These comprise issues that are unacceptable to FDMs who otherwise might donate. Two subdomains were identified: FDM is unfavorable towards donating tissues for research ($n=4$) and FDM wants certain tissues preserved/not procured for tissue donation ($n=4$). The first subdomain includes expressions of wanting to donate for

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transplantation but not for research. The second subdomain consists of statements such as not wanting the heart valves donated due to the patient's heart disease and not wanting certain bones donated due to their special value to the FDM or patient.

The attitude domains and subdomains, summarized in Table 9, generally mapped onto the Tripartite Model of Attitude Structure.

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Table 9

Domains and Subdomains of FDMs' Expressed Attitudes

Affective Component	n (%)	Behavioral Component	n (%)	Cognitive Component	n (%)
(A1) Donation invokes positive emotion		(B1) Patient's wishes		(C1) Donation is valuable	
FDM feels good about tissue donation.	65 (27.1)	FDM supports patient's wishes.	70 (29.2)	FDM believes tissue donation helps people/saves lives.	36 (15.0)
FDM is enthusiastic about tissue donation.	4 (1.7)	FDM had a discussion about donation with patient.	24 (10.0)	FDM believes it is 'the right thing to do.'	31 (12.9)
FDMs feel grateful.	4 (1.7)	FDM does NOT support patient's wishes	10 (4.2)	FDM believes using the tissue is better than wasting it.	18 (7.5)
(A2) Aversion to changing body after death		(B2) Pro-donation behaviors		(C2) False beliefs regarding eligibility	
FDM feels the patient has been through enough already.	35 (14.6)	FDM has discussed donation with family (and it was positive).	39 (16.3)	FDM believes patient's tissues are not suitable for donation.	45 (18.8)
FDM does not want patient's body to be touched/cut on.	7 (2.9)	FDM is a registered donor.	18 (7.5)	FDM believes tissue donation is only possible with cremation.	1 (0.4)
(A3) Donation invokes negative emotion		FDM has discussed donation with others (and it was positive).	5 (2.1)	(C3) Curiosity about negative physical changes	
FDM feels guilty about making a decision.	26 (10.8)	FDMs told the patient in the past that donation was 'a good thing to do'.	2 (0.8)	FDM believes donation will alter patient's appearance.	27 (11.3)
FDM feels tissue donation is barbaric.	6 (2.5)	(B3) Anti-donation behaviors		FDM believes/wants the patient to go out of the world the way s/he came into it.	2 (0.8)
(A4) Conditional donation		FDM discussed donation with family (and it was negative).	39 (16.3)	(C4) Money	
FDM is unfavorable towards donating tissues for research.	4 (1.7)	FDM discussed donation with others (and it was negative).	6 (2.5)	FDM believes it will cost him/her money to donate tissues.	8 (3.3)
FDM wants certain tissues preserved/not procured for tissue donation.	4 (1.7)	FDM is not a registered donor.	1 (0.4)	FDM believes that the tissue donation industry is all profit-driven.	1 (0.4)
		(B4) Direct past experience with donation		(C5) Donation process/timing	
		FDM is involved with donation in some way.	7 (2.9)	FDM believes tissue donation will delay the funeral.	6 (2.5)
		FDM has donated before.	1 (0.4)	FDM's concern of not being able to spend time with the patient before the donation.	1 (0.4)
				(C6) Religious beliefs	
				FDM thinks it's against patient's/his/her religion.	4 (1.7)
				FDM believes patient is still alive in some way.	1 (0.4)
Total	155		212		181

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Overall, 14 attitude domains and 34 subdomains were reported. FDMs individually expressed between 0 and 13 attitudes total ($M= 2.32$, $SD=1.99$) and from 0-3 subdomains within each domain. A plurality (64.6%) of FDMs expressed 2 or fewer and 35.4% expressed ≥ 3 or more attitudes. The majority of FDMs expressed either 0 ($n=32$, 13.3%), 1 ($n=66$, 27.5%) or 2 ($n=27$, 23.8%) attitudes. A summary of the frequencies of expressed attitudes is shown in Table 10 below.

Table 10
Distribution of Attitudes Expressed by FDMs

Number of attitudes expressed	$N=240$ n (%)
0	32 (13.3)
1	66 (27.5)
2	57 (23.8)
3	30 (12.5)
4	26 (10.8)
5	15 (6.3)
≥ 6	14 (5.8)

III. Comparison of TRs' Perceptions of FDMs' Attitudes and FDMs' Attitudes

The TRs' perceptions of FDMs' attitudes and the FDMs' attitudes are compared below.

Congruence of domains. Table 11 indicates that most of the domains and subdomains expressed by FDMs were also identified by TRs. Of the combined 15 domains identified, 13 were identical between TRs and FDMs. The domains that were not identical included money, expressed by FDMs but not mentioned by TRs, and distrust of medical/tissue industry, mentioned by TRs but not expressed by FDMs.

Congruence of subdomains. Forty-four subdomains were identified; 37 were identical between TRs and FDMs. The following subdomains were mentioned by TRs but not expressed by FDMs: patient will not feel the same as before, the patient cannot donate because s/he is dead, it's necessary to return to the hospital to donate, patient's body parts will be taken/stolen, not enough medical attention will be given to patient, and rich people are given preference for transplantation.

The subdomain mentioned by FDMs but not the TRs was that it will cost money to donate tissues.

Table 11

Congruence of Domains and Subdomains between TR and FDM Expressed Attitudes

Category	Domain <i>Sub-domain</i>	<u>TR Perspective</u>	<u>FDM Attitudes</u>
Affective	Aversion to changing body after death	✓	✓
	<i>FDM(s) do not want patient's body to be touched/cut on.</i>	✓	✓
	<i>FDM(s) feel the patient has been through enough already.</i>	✓	✓
	<i>FDM(s) want to remember the patient the way s/he was.</i>	✓	✓
	Donation invokes positive emotion	✓	✓
	<i>FDM(s) feels good about tissue donation.</i>	✓	✓
	<i>FDM is enthusiastic about tissue donation.</i>	✓	✓
	<i>FDM(s) feel grateful.</i>	✓	✓
	Donation invokes negative emotion	✓	✓
	<i>FDM(s) feels tissue donation is barbaric.</i>	✓	✓
	<i>FDM feels guilty about making a decision.</i>	✓	✓
	Conditional donation	✓	✓
	<i>FDM(s) is unfavorable towards donating tissues for research.</i>	✓	✓
	<i>FDM(s) wants certain tissues preserved/not procured for tissue donation.</i>	✓	✓
Behavioral	Patient's wishes	✓	✓
	<i>FDM(s) support patient's wishes.</i>	✓	✓
	<i>FDM(s) do NOT support patient's wishes.</i>	✓	✓
	<i>FDM(s) had a discussion with patient about donation.</i>	✓	✓
	Anti-donation behaviors	✓	✓
	<i>FDM(s) have discussed donation with family (and it was negative)</i>	✓	✓

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	<i>FDM(s) have discussed donation with others, not family (and it was negative)</i>	✓	✓
	<i>FDM(s) is not a registered donor.</i>	✓	✓
	Pro-donation behaviors	✓	✓
	<i>FDM(s) are registered donors.</i>	✓	✓
	<i>FDM(s) have discussed donation with family (and it was positive).</i>	✓	✓
	<i>FDM(s) have discussed donation with others (and it was positive).</i>	✓	✓
	<i>FDM(s) told the patient in the past that donation was 'a good thing to do'</i>	✓	✓
	Direct past experience with donation	✓	✓
	<i>FDM(s) are involved with donation in some way.</i>	✓	✓
	<i>FDM(s) has donated before.</i>	✓	✓
Cognitive	Negative physical changes	✓	✓
	<i>FDM(s) believe donation will alter patient's appearance.</i>	✓	✓
	<i>FDM(s) believe/want the patient to go out of the world the way s/he came into it.</i>	✓	✓
	<i>FDM(s) believe patient will not feel the same.</i>	✓	
	Distrust of medical/tissue industry	✓	
	<i>FDM(s) believe patient's body parts will be taken/stolen.</i>	✓	
	<i>FDM(s) believe not enough medical attention will be given to patient.</i>	✓	
	<i>FDM(s) believe tissue donation industry is sinister and manipulative.</i>	✓	✓
	<i>FDM(s) believe tissues will be wasted.</i>	✓	✓
	<i>FDM(s) believe patient's body will not be treated with respect.</i>	✓	✓
	<i>FDM(s) believe rich people are given preference for transplantation.</i>	✓	
	False beliefs regarding eligibility	✓	✓
	<i>FDM(s) believe patient's tissues are not suitable for donation.</i>	✓	✓
	<i>FDM(s) believe tissue donation is not possible because patient is dead.</i>	✓	
	<i>FDM(s) believes tissue donation is only possible with cremation.</i>	✓	✓
	Donation is valuable	✓	✓
	<i>FDM(s) believe tissue donation helps people/saves lives.</i>	✓	✓
	<i>FDM(s) believes it is 'the right thing to do.'</i>	✓	✓
	<i>FDM(s) believes using the tissue is better than wasting it</i>	✓	✓
	Religious beliefs	✓	✓
	<i>FDM(s) think it's against patient's/their religion.</i>	✓	✓
	<i>FDM(s) believes patient is still alive in some way.</i>	✓	✓
	Donation process/timing	✓	✓
	<i>FDM(s) believe tissue donation will delay the funeral.</i>	✓	✓
	<i>FDM(s) think they have to return to the hospital to donate patient's tissues.</i>	✓	

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<i>FDM(s) believes concern of not being able to spend time with the patient before the donation again.</i>	✓	✓
Money		✓
<i>FDM(s) believes it will cost him/her money to donate tissues.</i>		✓
<i>FDM(s) believes that the tissue donation industry is all profit-driven.</i>	✓	✓

Domain rankings. As shown in Table 12 below, TRs and FDMs endorsed similar domains but the frequency with which they were endorsed differed. While the patient's wishes domain was in the top 2 domains endorsed for each respondent group, aversion to changing the body after death was the most frequently endorsed for TRs but ranked 6th for FDMs. Along the same lines, the domain, negative physical changes, was ranked 3rd for TRs, while it ranked 7th for FDMs. The theme of the patient's appearance was emphasized by TRs, while FDMs mostly expressed patient's wishes and positive aspects of donation (i.e., donation is valuable, donation invokes positive emotion, and pro-donation behaviors). TRs and FDMs similarly ranked domains such as false beliefs regarding eligibility and donation invokes negative emotion.

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Table 12
TR and FDM Domain Rankings

TR	<i>n</i>	FDM	<i>n</i>
A1: Aversion to changing body after death	1	B1: Patient's wishes	2
B1: Patient's wishes	2	C1: Donation is valuable	5
C1: Distrust of medical/tissue industry	2	A1: Donation invokes positive emotion	6
C2: Negative physical changes	3	B2: Pro-donation behaviors	9
C3: False beliefs regarding eligibility	4	C2: False beliefs regarding eligibility	4
C4: Donation is valuable	5	B3: Anti-donation behaviors	8
A2: Donation invokes positive emotion	6	A2: Aversion to changing body after death	1
A3: Donation invokes negative emotion	6	A3: Donation invokes negative emotion	6
C5: Religious beliefs	7	C3: Curiosity about negative physical changes	3
C6: Donation process/timing	7	C6: Religious beliefs	7
B2: Anti-donation behaviors	8	B4: Direct past experience with donation	9
B3: Pro-donation behaviors	9	C5: Donation process/timing	7
B4: Direct past experience with donation	9	A4: Conditional donation	--
		C4: Money	--

Specific Aim 2: Assess the differences in attitude components between three groups of families (initially favorable, unsure, and unfavorable)

The identified attitude domains from Specific Aim 1 were used in Specific Aim 2 to determine their relationships with other variables such as FDM sociodemographics, initial response to tissue donation, and other FDM characteristics. A cluster analysis was performed to conduct an exploratory examination of how FDMs clustered together according to their attitudes. These analyses informed the multivariate analyses that further assessed the differences in attitudes between FDM initial response groups. The significant results from these analyses are described below.

Relationships between attitudes and FDM study variables. In Specific Aim 1, multiple relationships between the 3 FDM initial response groups (favorable, unsure, and unfavorable towards tissue donation) and the study's independent variables were investigated. As previously stated, FDMs' attitudes toward tissue donation, as well as their initial response to tissue donation have been found in past research to be highly and significantly predictive of tissue donation consent behavior (Rodrigue, Scott, and Oppenheim, 2003; Siminoff, Traino, and Gordon, 2010; Siminoff, Traino, and Gordon, 2011). Just as relationships between FDM initial response groups and study variables were explored, it was also important to explore the relationships between FDMs' expressed attitudes and these study variables in order to ascertain if there were any potentially confounding or moderating effects. Relationships were identified using chi squared tests of independence for categorical variables and t-tests for continuous variables. The results from these analyses are provided in Tables 13-15.

FDM sociodemographics and attitude domains. Significant relationships were found between attitude domains and gender, education, religion, income. These bivariate relationships are described below.

Gender. FDMs who expressed attitudes in the domain, donation invokes positive emotion (A1), were more likely than those who did not express such attitudes to be male (78.5% vs. 64.7%, $p < 0.05$).

Education. FDMs who expressed attitudes in the following domains were more likely to have more education (p 's < 0.01): donation invokes positive emotion (A1) ($M = 14.61$ vs. 13.34), pro-donation behaviors (B2) ($M = 14.38$ vs. 13.48), and donation is valuable (C1) ($M = 14.43$ vs. 13.44).

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Religion. FDMs who expressed attitudes in the domain curiosity about negative physical changes (C3) were more likely to be Catholic (37.1% vs. 17.3%, $p < 0.05$).

Income. FDMs who expressed attitudes in the following domains were more likely to have higher incomes ($p < 0.05$): donation invokes positive emotion (A1) ($M = \$58,000$ vs. $\$38,800$), direct past experience with donation (B4) ($M = \$86,700$ vs. $\$43,600$), and donation is valuable (C1) ($M = \$52,600$ vs. $\$41,700$).

FDM knowledge of patient's wishes and attitude domains. FDMs who expressed attitudes in the following domains were more likely to believe that their loved one wanted to donate tissues ($p < 0.05$): donation invokes positive emotion (A1) (86.8% vs. 43.0%), patient's wishes (B1) (61.7% vs. 52.2%), pro-donation behaviors (B2) (82.8% vs. 46.7%), donation is valuable (C1) (84.1% vs. 45.2%), and curiosity about negative physical changes (C3) (75.0% vs. 52.8%). FDMs who expressed attitudes in the following domains were less likely to think that their loved one wanted to donate tissues ($p < 0.05$): aversion to changing body after death (A2) (43.6% vs. 57.7%) and anti-donation behaviors (B3) (39.1% vs. 59.3%). FDMs with attitudes in the following domains were more likely to confuse organs with tissues ($p < 0.05$): pro-donation behaviors (A1) (19.0% vs. 8.8%), donation is valuable (C1) (22.2% vs. 7.3%), and false beliefs regarding eligibility (C2) (22.2% vs. 8.7%).

FDM initial attitudes and attitude domains. FDMs who expressed attitudes in the following domains were more likely to be initially favorable towards tissue donation and have more positive attitudes overall towards tissue donation ($p < 0.05$): donation invokes positive emotion (A1) (70.6% vs. 18.6%; $M = 51.74$ vs. 47.48), pro-donation behaviors (B2)

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(53.4% vs. 26.9%; $M = 51.78$ vs. 47.70), and donation is valuable (C1) (60.3% vs. 23.7%; $M = 51.65$ vs. 47.63).

FDMs who expressed attitudes in the following domains were more likely to be initially unfavorable toward tissue donation ($p's < 0.05$): aversion to changing body after death (A2) (59.0% vs. 28.4%) and donation invokes negative emotion (A3) (53.3% vs. 30.5%). FDMs who expressed attitudes the domain anti-donation behaviors (B3) were more likely to be initially unsure and unfavorable towards tissue donation (54.3% vs. 28.4% and 39.1% vs. 32.0%, respectively, $p < 0.001$).

Other FDM characteristics and attitude domains. Significant relationships were found between attitude domains and willingness to donate organs and tissues, relational communication with TR, initial receptivity to tissue donation, level of surprise by request, and time spent discussing tissue donation during the request. These relationships are described below.

FDM willingness to donate own organs and tissues. FDMs who expressed attitudes in the following domains were more likely to be willing to donate their own organs and tissues, respectively ($p's < 0.05$): donation invokes positive emotion (A1) (89.7% vs. 63.2% and 91.2% vs. 61.0%), pro-donation behaviors (B2) (89.7% vs. 64.6% and 89.7% vs. 63.2%), and donation is valuable (C1) (85.7% vs. 65.3% and 87.3% vs. 63.3%). FDMs who expressed attitudes in the domain anti-donation behaviors (B3) were less willing to donate their tissues (56.5% vs. 72.7%, $p < 0.05$).

Relational communication with TR. FDMs who expressed attitudes in the following domains were more likely to have better communications with TRs ($p's < 0.05$): donation invokes positive emotion (A1) ($M = 81.86$ vs. 70.18), pro-donation behaviors (B2) ($M = 81.11$

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vs. 71.06), donation is valuable (C1) ($M=83.47$ vs. 69.94), and curiosity about negative physical changes (C3) ($M= 83.45$ vs. 72.17). FDMs who expressed attitudes in the following domains were more likely to have worse communications with TRs: aversion to changing body after death (A2) ($M= 67.58$ vs. 74.64) and anti-donation behaviors (B3) ($M= 67.72$ vs. 74.86).

Initial receptivity to tissue donation. FDMs who expressed attitudes in the following domains were more receptive to tissue donation initially ($p's<0.05$): donation invokes positive emotion (A1) ($M= 6.15$ vs. 4.21), conditional donation (A4) ($M= 6.50$ vs. 4.71), pro-donation behaviors (B2) ($M=5.93$ vs. 4.39), donation is valuable (C1) ($M= 6.19$ vs. 4.25), and curiosity about negative physical changes (C3) ($M= 5.86$ vs. 4.62). FDMs who expressed attitudes in the following domains were less receptive to tissue donation initially ($p's<0.05$): aversion to changing body after death (A2) ($M= 3.31$ vs. 5.06), donation invokes negative emotion (A3) ($M= 3.72$ vs. 4.91), and anti-donation behaviors (B3) ($M= 3.52$ vs. 5.05).

Level of surprise by request. FDMs who expressed attitudes in the domain donation invokes negative emotion (A3) were more likely to be surprised by the request ($M= 5.57$ vs. 4.13, $p<0.01$). FDMs who expressed attitudes in the following domains were less likely to be surprised by the request ($p's<0.05$): donation invokes positive emotion (A1) ($M=3.66$ vs. 4.57) and donation is valuable (C1) ($M= 3.73$ vs. 4.52).

Time spent discussing tissue donation. FDMs who expressed attitudes in the following domains were more likely to have spent a longer amount of time discussing tissue donation ($p's<0.05$): donation invokes positive emotion (A1) ($M= 28.04$ vs. 13.26), pro-donation behaviors (B2) ($M= 28.93$ vs. 13.79), direct past experience with donation

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(B4) ($M = 33.57$ vs. 16.97), donation is valuable (C1) ($M = 31.19$ vs. 12.56), and curiosity about negative physical changes (C3) ($M = 25.26$ vs. 16.42).

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Table 13

Significant Associations of FDM Study Variables with FDM Affective Attitude Domains for N=240 FDMs

Study Variable	A1: Donation invokes positive emotion			A2: Aversion to changing body after death			A3: Donation invokes negative emotion			A4: Conditional donation		
	Yes	No	χ^2 ; p-value	Yes	No	χ^2 ; p-value	Yes	No	χ^2 ; p-value	Yes	No	χ^2 ; p-value
<i>FDM characteristics</i>												
<i>FDM sex</i>												
Female	44 (64.7)	135 (78.5)	4.88; 0.03	32 (82.1)	147 (73.1)	NS	21 (70.0)	158 (75.2)	NS	----	----	----
<i>Religious affiliation</i>												
Protestant	42 (62.7)	96.8 (56.3)		24(61.5)	115.8(57.6)		16.8 (56.0)	123 (58.5)				
Catholic	12 (17.9)	35 (20.3)	NS	5 (12.8)	42 (20.9)	NS	4 (13.3)	43 (20.5)	NS	----	----	----
Other	13 (19.4)	40.2 (23.4)		10 (25.6)	43.2 (21.5)		9.2 (30.7)	44 (21.0)				
<i>Education, mean (SD)</i>	14.61 (2.56)	13.34 (2.14)	3.89; 0.000	13.21(2.46)	13.80(2.98)	NS	14.10(1.95)	13.64 (2.38)	NS	14.63(2.26)	13.67(2.33)	NS
<i>Income, mean (SD)</i>	6.80 (3.52)	4.88 (2.93)	4.19; 0.000	5.08 (2.94)	5.48 (3.23)	NS	5.60 (3.22)	5.39 (3.18)	NS	4.83 (3.37)	5.43 (3.18)	NS
<i>FDM knowledge</i>												
<i>Thought patient wanted to donate</i>	59 (86.8)	74 (43.0)	37.8; 0.00	17 (43.6)	116 (57.7)	7.28; 0.026	13 (43.3)	120 (57.1)	NS	----	----	----
<i>FDM confused organs with tissues</i>	11 (16.2)	16 (9.3)	NS	----	----	----	----	----	----	----	----	----
<i>FDM attitudes</i>												
<i>FDM initial response to tissue donation</i>												
Favorable	48 (70.6)	32 (18.6)	60.37;	5 (12.8)	75 (37.3)	15.43;	5 (16.7)	75 (35.7)	7.09;	----	----	----
Unsure	13 (19.1)	67 (39.0)	0.000	11 (28.2)	69 (34.3)	0.000	9 (30.0)	71 (33.8)	0.029			
Unfavorable	7 (10.3)	73 (42.4)		23 (59.0)	57 (28.4)		16 (53.3)	64 (30.5)				
<i>FDM tissue donation attitudes, mean (SD)</i>	51.74 (5.9)	47.48 (7.8)	4.07; 0.000	46.49(7.56)	49.11(7.47)	NS	46.77 (7.8)	48.96 (7.5)	NS	52.38 (3.9)	48.56 (7.6)	NS
<i>Other</i>												

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<i>Willing to donate organs</i>	61 (89.7)	108 (63.2)	16.56; 0.00	24 (61.5)	145 (72.5)	NS	17 (56.7)	152 (72.7)	NS	----	----	----
<i>Willing to donate tissues</i>	62 (91.2)	105 (61.0)	20.9; 0.00	24 (61.5)	143 (71.1)	NS	17 (56.7)	150 (71.4)	NS	----	----	----
<i>FDM affect, mean (SD)</i>	23.93 (7.4)	21.0 (8.7)	2.42; 0.016	19.63(10.4)	22.24 (8.0)	NS	25.6 (7.4)	21.28 (8.5)	2.64; 0.009	23.13 (5.5)	21.78 (8.6)	NS
<i>FDM's relational communication with TR, mean (SD)</i>	81.86(11.59)	70.18(15.9)	5.22; 0.000	67.58(14.5)	74.64(15.7)	-2.51; 0.012	71.21(15.6)	73.98 (15.6)	NS	75.14(18.1)	73.61(15.6)	NS
<i>FDM initial receptivity to tissue donation, mean (SD)</i>	6.15 (1.24)	4.21 (2.17)	6.9; 0.000	3.31 (1.96)	5.06 (2.05)	-4.89; 0.000	3.72 (2.15)	4.91 (2.1)	-2.85; 0.006	6.50 (0.76)	4.71 (2.14)	2.36; 0.019
<i>FDM's level of surprise at request, mean (SD)</i>	3.66 (2.46)	4.57 (2.55)	-2.5; 0.013	4.31 (2.76)	4.31 (2.52)	NS	5.57 (2.16)	4.13 (2.56)	2.92; 0.004	3.13 (2.64)	4.36 (2.55)	NS
<i>Time spent discussing donation (minutes), mean (SD)</i>	28.04(21.04)	13.26(20.6)	4.87; 0.000	12.61(31.7)	18.39(18.3)	NS	20.18(37.2)	17.33 (17.8)	NS	28.86(30.1)	17.32(20.9)	NS

Note. Values are count (percent) unless otherwise noted, where mean (standard deviation) and t and p-values are reported; "----" indicates that chi-squared analysis was unable to be performed due to one of the cells having an expected count less than 5.

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Table 14

Significant Associations of FDM Study Variables with FDM Behavioral Attitude Domains for N=240 FDMs

Study Variable	B1: Patient's wishes			B2: Pro-donation behaviors			B3: Anti-donation behaviors			B4: Direct past experience with donation		
	Yes	No	χ^2 ; p-value	Yes	No	χ^2 ; p-value	Yes	No	χ^2 ; p-value	Yes	No	χ^2 ; p-value
<i>FDM characteristics</i>												
<i>FDM sex</i>												
Female	55 (67.9)	124 (78.0)	NS	39 (67.2)	140 (76.9)	NS	37 (80.4)	142 (73.2)	NS	----	----	----
<i>Religious affiliation</i>												
Protestant	41.6 (51.4)	98.2 (61.8)	NS	34 (58.6)	105.8 (58.1)	NS	27 (58.7)	112.8 (58.1)	NS	----	----	----
Catholic	14.4 (17.8)	32.6 (20.5)		10 (17.2)	37 (20.3)		8 (17.4)	39 (20.1)				
Other	25 (30.9)	28.2 (17.7)		14 (24.1)	39.2 (21.5)		11 (23.9)	42.2 (21.8)				
<i>Education (mean years, SD)</i>	14.11 (2.4)	13.49 (2.27)	NS	14.38 (2.58)	13.48 (2.2)	2.59; 0.01	13.22(1.76)	13.81 (2.44)	NS	14.29 (1.5)	13.68(2.35)	NS
<i>Income (mean, SD)</i>	5.84 (3.21)	5.19 (3.15)	NS	6.11 (3.60)	5.19 (3.01)	NS	4.82 (2.96)	5.61 (3.18)	NS	9.67 (3.45)	5.36 (3.08)	3.37; 0.001
<i>FDM knowledge</i>												
<i>Thought patient wanted to donate</i>	50 (61.7)	83 (52.2)	8.72; 0.013	48 (82.8)	85 (46.7)	24.08; 0.00	18 (39.1)	115 (59.3)	6.67; 0.036	----	----	----
<i>FDM confused organs with tissues</i>	10 (12.3)	17 (10.7)	NS	11 (19.0)	16 (8.8)	6.03; 0.049	5 (10.9)	22 (11.3)	NS	----	----	----
<i>FDM attitudes</i>												
<i>FDM initial response to tissue donation</i>												
Favorable	31 (38.3)	49 (30.8)	NS	31 (53.4)	49 (26.9)	21.6; 0.000	3 (6.5)	77 (39.7)	20.39; 0.000	----	----	----
Unsure	25 (30.9)	55 (34.6)		21 (36.2)	59 (32.4)		25 (54.3)	55 (28.4)				
Unfavorable	25 (30.9)	55 (34.6)		6 (10.3)	74 (40.7)		18 (39.1)	62 (32.0)				
<i>FDM tissue donation attitudes, mean (SD)</i>	49.99 (7.5)	48.03 (7.5)	NS	51.78 (6.3)	47.70 (7.6)	3.68; 0.000	47.70 (8.2)	48.92 (7.4)	NS	53.29 (4.7)	48.55 (7.6)	NS
<i>Other</i>												

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<i>Willing to donate organs</i>	58 (72.5)	111 (69.8)	NS	52 (89.7)	117 (64.6)	13.27; 0.00	27 (58.7)	142 (73.6)	NS	----	----	----
<i>Willing to donate tissues</i>	58 (71.6)	109 (68.6)	NS	52 (89.7)	115 (63.2)	14.56; 0.00	26 (56.5)	141 (72.7)	4.59; 0.032	----	----	----
<i>FDM affect, mean (SD)</i>	24.0 (7.8)	20.70 (8.6)	2.89; 0.004	22.35 (9.3)	21.66 (8.2)	NS	21.54 (8.9)	21.89 (8.4)	NS	23.0 (7.3)	21.79 (8.5)	NS
<i>FDM's relational communication with TR, mean (SD)</i>	74.25(16.0)	73.37 (15.45)	NS	81.11(13.9)	71.06 (15.45)	4.18; 0.000	67.72(16.0)	74.86 (15.33)	-2.68; 0.008	82.17(13.4)	73.41(15.6)	NS
<i>FDM initial receptivity to tissue donation, mean (SD)</i>	5.05 (1.96)	4.62 (2.21)	NS	5.93 (1.6)	4.39 (2.2)	5.01; 0.000	3.52 (1.97)	5.05 (2.07)	-4.45; 0.000	6.14 (1.22)	4.73 (2.15)	NS
<i>FDM's level of surprise at request, mean (SD)</i>	4.05 (2.53)	4.45 (2.57)	NS	3.81 (2.53)	4.47 (2.55)	NS	4.59 (2.59)	4.25 (2.55)	NS	4.00 (2.89)	4.32 (2.55)	NS
<i>Time spent discussing donation (minutes), mean (SD)</i>	19.50(21.5)	16.78 (21.22)	NS	28.93(28.9)	13.79 (17.45)	4.81; 0.000	15.66(30.4)	18.20 (18.54)	NS	33.57(27.6)	16.97(21.4)	2.00; 0.045

Note. Values are count (percent) unless otherwise noted, where mean (standard deviation) and t and p-values are reported; "----" indicates that chi-squared analysis was unable to be performed due to one of the cells having an expected count less than 5.

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Table 15

Significant Associations of FDM Study Variables with FDM Cognitive Attitude Domains for N=240 FDMs

Study Variable	C1: Donation is valuable			C2: False beliefs regarding eligibility			C3: Curiosity about negative physical changes			C4: Money			C5: Donation process/timing			C6: Religious beliefs			
	Yes	No	χ^2 ; p-value	Yes	No	χ^2 ; p-value	Yes	No	χ^2 ; p-value	Yes	No	χ^2 ; p-value	Yes	No	χ^2 ; p-value	Yes	No	χ^2 ; p-value	
FDM characteristics																			
FDM sex																			
Female	43 (68.3)	136(76.8)	NS	36 (80.0)	143 (73.3)	NS	22 (78.6)	157 (74.1)	NS	----	----	----	----	----	----	----	----	----	
Religious affiliation																			
Protestant	39.8 (63.2)	100 (56.5)		27.8 (61.8)	112 (57.4)		15.6 (55.7)	124.2 (58.6)		----	----	----	----	----	----	----	----	----	
Catholic	7 (11.1)	40 (22.6)	NS	8 (17.8)	39 (20.0)	NS	10.4 (37.1)	36.6 (17.3)	8.29; 0.017										
Other	16.2 (25.7)	37 (20.9)		9.2 (20.4)	44 (22.6)		2 (7.1)	51.2 (24.1)											
Education (mean years, SD)	14.43(2.56)	13.44 (2.19)	2.94; 0.004	13.87(2.8)	13.66(2.21)	NS	14.29 (2.6)	13.62 (2.3)	NS	14.88 (2.6)	13.66(2.3)	NS	12.71 (2.1)	13.73 (2.3)	NS	14.6(2.4)	13.68(2.3)	NS	
Income (mean, SD)	6.26 (3.40)	5.17 (3.01)	2.33; 0.020	5.62(3.07)	5.42 (3.168)	NS	6.46 (3.24)	5.33 (3.12)	NS	6.75 (3.20)	5.41(3.14)	NS	5.86 (2.67)	5.45 (3.19)	NS	4.60(2.30)	5.49(3.19)	NS	
FDM knowledge																			
Thought patient wanted to donate	53 (84.1)	80 (45.2)	30.43; 0.00	30 (66.7)	103 (52.8)	NS	21 (75.0)	112 (52.8)	6.24; 0.044	----	----	----	----	----	----	----	----	----	
FDM confused organs with tissues	14 (22.2)	13 (7.3)	10.3; 0.001	10 (22.2)	17 (8.7)	6.68; 0.010	----	----	----	----	----	----	----	----	----	----	----	----	
FDM attitudes																			
FDM initial response to tissue donation																			
Favorable	38 (60.3)	42 (23.7)	30.61; 0.001	12 (26.7)	68 (34.9)	NS	11(39.3)	69 (32.5)	NS	----	----	----	----	----	----	----	----	----	

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Unsure	17 (27.0)	63 (35.6)	0.000	18 (40.0)	62 (31.8)		13 (46.4)	67 (31.6)										
Unfavorable	8 (12.7)	72 (40.7)		15 (33.3)	65 (33.3)		4 (14.3)	76 (35.8)										
<i>FDM tissue donation attitudes, mean (SD)</i>																		
	51.65(6.3)	47.63 (7.7)	3.74; 0.000	48.4 (7.8)	48.75 (7.5)	NS	47.75 (7.6)	48.81 (7.5)	NS	48.50 (7.3)	48.7 (7.6)	NS	51.0 (10.0)	48.62 (7.5)	NS	49.0 (5.5)	48.7 (7.6)	NS
<i>Other</i>																		
<i>Willing to donate organs</i>	54 (85.7)	115 (65.3)	9.30; 0.002	32 (71.1)	137 (70.6)	NS	22 (78.6)	147 (69.7)	NS	----	----	----	----	----	----	----	----	----
<i>Willing to donate tissues</i>	55(87.3)	112 (63.3)	12.67; 0.00	33 (73.3)	134 (68.7)	NS	22 (78.6)	145 (68.7)	NS	----	----	----	----	----	----	----	----	----
<i>FDM affect, mean (SD)</i>	22.56 (9.2)	21.56 (8.2)	NS	21.80(9.8)	21.83 (8.2)	NS	21.79 (8.7)	21.83 (8.5)	NS	25.0(10.8)	21.71(8.4)	NS	20.50(10.3)	21.86 (8.4)	NS	28.0 (5.1)	21.69(8.5)	NS
<i>FDM's relational communication with TR, mean (SD)</i>	83.47 (11.99)	69.94(15.33)	6.16; 0.000	72.20(14.66)	74.02(15.87)	NS	83.45(14.30)	72.17(15.41)	3.30; 0.001	82.86(13.25)	73.34(15.63)	NS	71.0(17.18)	73.74(15.61)	NS	76.80(18.99)	73.58(15.58)	NS
<i>FDM initial receptivity to tissue donation, mean (SD)</i>	6.19 (1.18)	4.25 (2.17)	2.92; 0.004	4.93 (2.02)	4.73 (2.17)	NS	5.86 (1.35)	4.62 (2.18)	2.92; 0.004	5.88 (1.36)	4.73 (2.15)	NS	5.43 (1.90)	4.75 (2.14)	NS	4.80 (2.49)	4.77 (2.13)	NS
<i>FDM's level of surprise at request, mean (SD)</i>	3.73 (2.64)	4.52 (2.5)	-2.13; 0.035	4.93 (2.39)	4.17 (2.58)	NS	4.19 (2.48)	4.33 (2.57)	NS	3.88 (2.8)	4.33 (2.55)	NS	4.00 (3.0)	4.32 (2.55)	NS	4.40 (3.13)	4.31 (2.55)	NS
<i>Time spent discussing donation (minutes), mean (SD)</i>	31.19(29.00)	12.56(15.88)	6.05; 0.000	20.10(20.54)	17.11(21.49)	NS	25.26(22.62)	16.42(21.42)	2.00; 0.046	34.17(28.36)	17.22(20.94)	NS	16.40(10.11)	17.74 (21.5)	NS	22.80 (20.0)	17.58(21.35)	NS

Note. Values are count (percent) unless otherwise noted, where mean (standard deviation) and t and p-values are reported; “---” indicates that chi-squared analysis was unable to be performed due to one of the cells having an expected count less than 5.

Cluster analysis of FDM attitude domains. A cluster analysis was performed to explore whether grouping or clusters could be defined through an analysis of the total dataset of attitudinal domains. This exploratory technique does not presuppose knowledge of group membership or which elements belong to which clusters (Aldenderfer and Blashfield, 1984). This analysis helped to reveal whether there were manageable groupings from the large initial dataset and informed the subsequent multivariate analyses that were performed using MANCOVA and discriminant function analysis. FDMs were assigned to only one cluster.

Initial examination of the clusters revealed there was a cluster of individuals who did not endorse any attitudes on any of the domains ($n = 101$). The decision was made to remove these non-endorsers in order to be certain the presence of this extreme cluster did not cloud assessment of the remaining cluster solutions. The resulting iterative process yielded a meaningful 3-cluster solution.

In order to evaluate how the group that did not endorse any attitudes differed in important ways from those who did, other statistical analyses (such as, chi square and t-test statistics) assessing these differences were performed. Those who expressed attitudes (in clusters 1-3) were more likely to be Caucasian (26.0% vs. 15.1%, $X^2(1, N=240)=4.37$, $p=0.037$), to have more positive attitudes towards tissue donation generally ($M=49.55$ vs. 47.5, $t(238)=2.1$, $p=0.036$), to confuse organs with tissues (15.1% vs. 5.9%, $X^2(1, N=240)=4.92$, $p=0.026$), and to be initially more receptive to the tissue donation request ($M=5.16$ vs. 4.23, $t(238)=3.39$, $p=0.001$). A Mann-Whitney U test ($M=22.61$ vs. 20.75, $t(238)=1.68$, $p=0.047$) revealed those with attitudes were also significantly more likely to demonstrate more positive affect.

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There were very small differences between the clusters. Clusters 2 and 3 were most similar (*distance*=1.229), followed by clusters 1 and 2 (*distance*=1.342). Clusters 1 and 3 were most dissimilar (*distance*=1.406). Compared to other cluster solutions, the 3-cluster solution most closely mapped onto the Tripartite Model of Attitude Structure. Two of the clusters included one domain, while one included three domains from different attitude component categories. Specifically, FDMs in the second cluster expressed attitudes in the patient's wishes domain, which is descriptive of the behavioral component of attitudes. FDMs in the third cluster expressed attitudes in the false beliefs regarding eligibility domain, which is descriptive of the cognitive component of attitudes. Finally, FDMs in the first cluster expressed attitudes in the domains, donation invokes positive emotion, pro-donation behaviors, and donation is valuable, which are descriptive of the affective component of attitudes. In total, 5 out of the 14 domains mapped onto the Tripartite Model of Attitude Structure.

These 3 clusters and their proposed labels are described below in Table 16.

Cluster 1: Affect. Cluster 1 consists of 51 FDMs with attitudes in domains A1, donation invokes positive emotion, B2, pro-donation behaviors, and C1, donation is valuable. All three domains represent a cluster of FDMs that are favorable towards tissue donation that can feasibly be tied to positive affect. Thus, cluster 1 is called "affect".

Cluster 2: Behavior. Cluster 2 consists of 49 FDMs with attitudes in domain B1, patient's wishes. The prevalent attitudes for FDMs in this cluster were behavioral attitudes. This cluster is therefore labeled "behavior."

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Cluster 3: Cognition. Cluster 3 consists of 39 FDMs who expressed attitudes in domain C2, false beliefs regarding eligibility. The attitudes expressed in this cluster of FDMs are negative cognitive attitudes. This cluster is labeled “cognition.”

Table 16
K-Means Cluster Analysis for 3 Groups

Attitude Domain	Cluster		
	1	2	3
(A1) Donation invokes positive emotion	1	0	0
(A2) Aversion to changing body after death	0	0	0
(A3) Donation invokes negative emotion	0	0	0
(A4) Conditional donation	0	0	0
(B1) Patient's wishes	0	1	0
(B2) Pro-donation behaviors	1	0	0
(B3) Anti-donation behaviors	0	0	0
(B4) Direct past experience with donation	0	0	0
(C1) Donation is valuable	1	0	0
(C2) False beliefs regarding eligibility	0	0	1
(C3) Curiosity about negative physical changes	0	0	0
(C4) Money	0	0	0
(C5) Donation process/timing	0	0	0
(C6) Religious beliefs	0	0	0
Proposed cluster label	Affect	Behavior	Cognition

Note. “1” represents at least 1 expressed attitude in the corresponding attitude domain by FDMs in the respective cluster.

Multivariate analyses of FDM attitudes. First, the preliminary results for the MANCOVA with empirically-driven covariates are reported. Since none of the covariates were significant, the results from the MANOVA, without the covariates, are reported instead. Following this are the results from the MANCOVA with data-driven covariates. Additional analyses were performed and are reported below.

MANCOVA with theory-driven covariates. One-way between-groups MANCOVA was conducted to investigate whether FDM group means were different in terms of attitudes after controlling for covariates. Three dependent variables were included: affective attitudes, behavioral attitudes, and cognitive attitudes. Each of the dependent variables consisted of the sum of the attitude domains described earlier for each category. The independent or fixed variable was FDM group (initially favorable, initially unsure, and initially unfavorable). Five covariates were used in this analysis: FDM race, FDM education, FDM religion, FDM relationship to patient, and thought patient wanted to donate. The covariates were determined a priori from the previous research in the field of organ and tissue donation, and are thus, empirically driven.

The MANCOVA results indicated there was a statistically significant difference between FDM initial response groups on the combined dependent variables (*Wilks' Lambda*=0.915, $F(6, 460)=3.49$, $p=0.002$, partial eta-squared=0.044). None of the covariates were significant; therefore, a MANOVA, without the covariates, was conducted.

MANOVA. A one-way between-groups MANOVA was performed to examine FDM initial response group differences in attitudes. Three dependent variables were used: affective attitudes, behavioral attitudes, and cognitive attitudes. The independent variable was FDM initial response group. There was a statistically significant difference between

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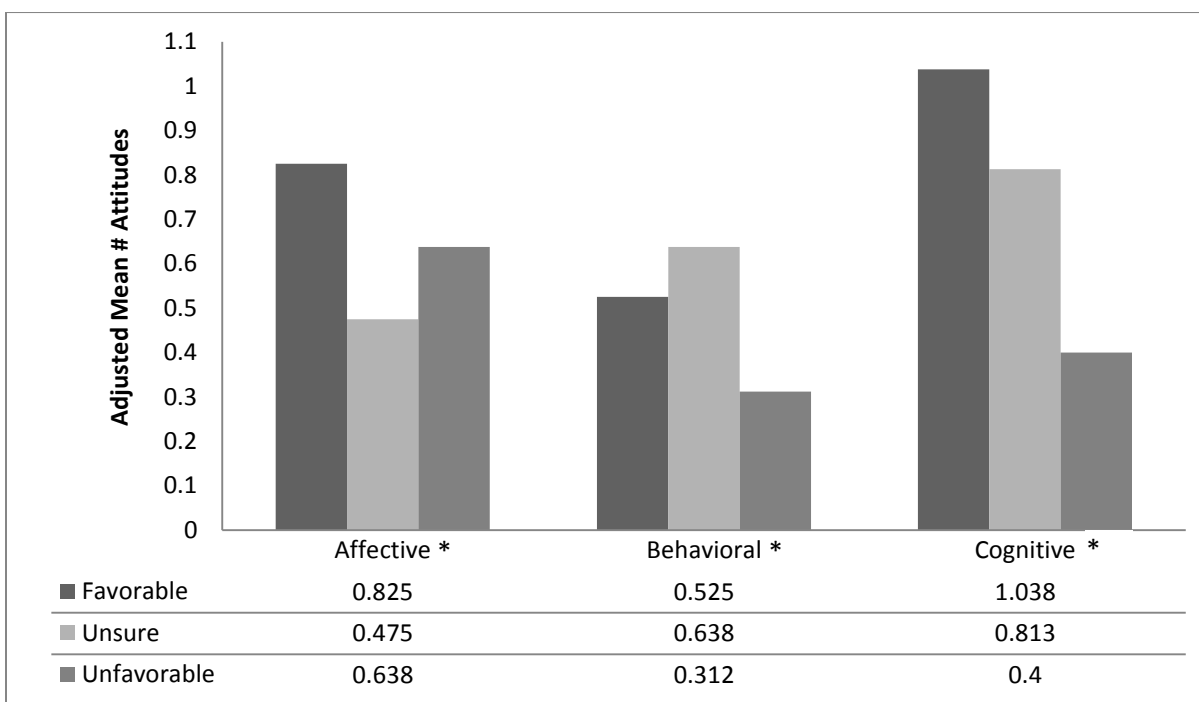
FDM initial response group on the combined dependent variables, (*Wilks' Lambda* = 0.864, $F(6, 470) = 5.94, p < 0.0001, \text{partial eta squared} = 0.071$). Each attitude component was statistically significant both before (at 0.05 alpha level) and after using a Bonferroni adjustment (alpha level of 0.017). Specifically, statistically significant differences between FDM initial response groups were found for affective attitudes, $F(2, 237) = 4.22, p = 0.016, \text{partial eta squared} = 0.034$, behavioral attitudes, $F(2, 237) = 5.08, p = 0.007, \text{partial eta squared} = 0.041$, and cognitive attitudes, $F(2, 237) = 8.32, p < 0.0001, \text{partial eta squared} = 0.066$.

Pairwise comparisons using Tukey's LSD with an alpha level of 0.05 indicated that there were significant differences in affective attitudes between FDMs that were initially favorable and unsure ($M_{\text{diff}}=0.350, SE=0.121, 95\% CI= [0.112, 0.588]$); in behavioral attitudes between FDMs that were initially favorable and unfavorable ($M_{\text{diff}}=0.213, SE=0.104, 95\% CI= [0.009, 0.416]$) and FDMs that were initially unsure and unfavorable ($M_{\text{diff}}=0.325, SE=0.104, 95\% CI= [0.121, 0.529]$); and in cognitive attitudes between FDMs that were initially favorable and unfavorable ($M_{\text{diff}}=0.638, SE=0.159, 95\% CI= [0.325, 0.950]$) and FDMs that were initially unsure and unfavorable ($M_{\text{diff}}=0.410, SE=0.159, 95\% CI= [0.100, 0.725]$). The mean attitudes for each FDM group are provided in Table 17.

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Table 17

Mean Affective, Behavioral, and Cognitive Attitudes for Three FDM Groups Indicated by MANOVA



Note. * = Significant at the alpha level of 0.017.

MANCOVA with data-driven covariates. A one-way between-groups MANCOVA was conducted to investigate differences in attitude domains between 3 groups of FDMs, with two covariates selected as a result of exploratory analysis. The two covariates included in the model were confusion of tissues with organs and time spent discussing tissue donation.

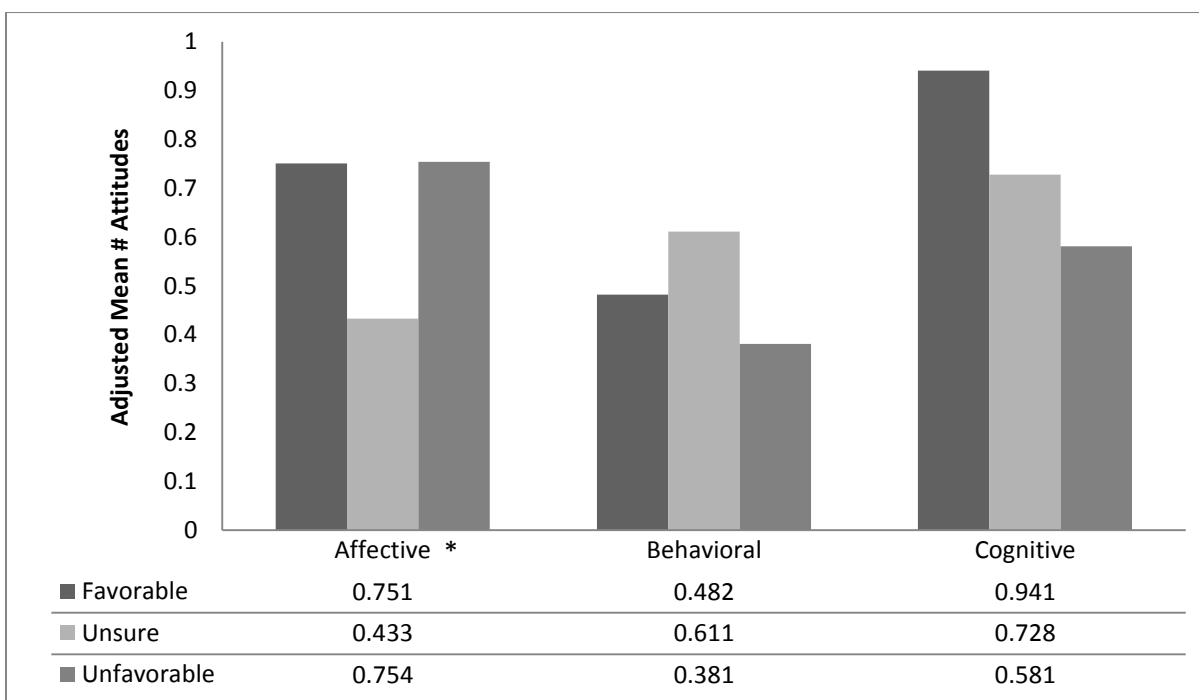
The MANCOVA indicated there was a statistically significant difference between FDM initial response groups on the combined dependent variables (*Wilks' Lambda*=0.904, $F(6, 460)=4.01, p<0.0001$), *partial eta-squared*=0.49. As expected, the two covariates had significant effects on the combined dependent variables: time spent discussing donation (*Wilks' Lambda*=0.888, $F(3, 230)=9.81, p<0.0001$), *partial eta-squared*=0.112, and confusion between tissues and organs (*Wilks' Lambda*=0.887, $F(3, 230)=9.9, p<0.0001$), *partial eta-squared*=0.113.

The only group mean that was significant both before and after applying a Bonferroni adjusted alpha level of 0.017 (or 0.05/3) was affective attitudes ($F(2, 237)=5.00, p=0.008, \text{partial eta-squared}=0.041$). Post-hoc analyses using Tukey's LSD was used to adjust for multiple comparisons. The initially favorable FDM group was significantly different from the initially unsure FDM group ($M_{diff}=0.318, SE=0.12, 95\% CI= [0.088, 0.548]$) and the initially unfavorable FDM was significantly different from the initially unsure FDM group ($M_{diff}=0.322, SE=0.12, 95\% CI= [0.084, 0.559]$). The adjusted means (# attitudes), after controlling for the two covariates, are provided below in Table 18.

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Table 18

Adjusted Means on Affective, Behavioral, and Cognitive Attitudes for the Three FDM Groups Indicated by MANCOVA



*Note. * = Significant at the alpha level of 0.017.*

Additional analyses. An analogous analysis to the MANOVA, a discriminant function analysis, was also conducted in order to triangulate the data analysis and determine which attitudes discriminated the 3 FDM groups. The findings from these analyses are discussed below.

Discriminant function analyses. A discriminant function analysis (DFA) was conducted to predict which attitudes distinguish between FDM initial response groups. Predictor variables were sum scores of affective, behavioral, and cognitive attitudes. Similar to the MANOVA performed and described above, tests for the equality of group means indicated that there were significant differences for all 3 sum attitude components: affective attitudes, $F(2, 237) = 4.22, p=0.016$; behavioral attitudes, $F(2, 237)=5.08, p=0.007$; and cognitive attitudes, $F(2, 237)=8.32, p<0.0001$. The DFA revealed a significant association between groups and all predictors, accounting for 66.7% of between group variability. Closer analysis of the structure matrix, however, revealed only one significant predictor, specifically behavioral attitudes (0.648), with affective and cognitive attitudes being poor predictors of FDM group membership. The cross-validated classification showed that overall, 47.5% of FDMs were correctly classified on the basis of their expressed attitudes.

On a more granular level, and in an attempt to determine which specific attitude domains best predicted FDM initial response group membership, a step-wise discriminant function analysis was conducted. The critical significance level for “F to remove” was set to 0.01 for entry and to 0.05 for removal. The predictor variables were the sum scores for the 14 attitude domains described earlier: A1-A4, B1-B4, and C1-C6. Tests for the equality of group means indicated that there were significant differences for 7 (A1-A4, B2, B3, and C1;

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p 's<0.05) out of 14 attitude domains. Four steps, or four attitude domains that minimized the overall Wilks' Lambda value, were entered. These attitude domains were A1 or donation invokes positive emotion (*Wilks' lambda*=0.795, $F(2, 237)=30.51$, $p<0.0001$), B3 or anti-donation behaviors (*Wilks' lambda*=0.742, $F(4, 472)=18.96$, $p<0.0001$), B2 or pro-donation behaviors (*Wilks' lambda*=0.708, $F(6, 470)=14.79$, $p<0.0001$), and A2 or aversion to changing body after death (*Wilks' lambda*=0.674, $F(8, 463)=12.77$, $p<0.0001$). Two discriminate functions showed significant associations between groups and selected predictors, with the first function accounting for 87.0% of between group variability and the second function accounting for 13.0% of between group variability. Closer analysis of the structure matrix revealed only two significant predictors for the first function, specifically A1 (0.801) and B2 (0.489), and two significant predictors for the second function, specifically B3 (0.669) and A2 (-0.457). The cross-validated classification showed that, overall, 57.1% were correctly classified. Finally, the classification function coefficients, shown below in Table 19, revealed that FDMs with expressed attitudes in domains A1 (donation invokes positive emotion) discriminated initially favorable FDMs from initially unsure and unfavorable FDMs (2.712 vs. 0.845 and 0.528, respectively) and B2 (pro-donation behaviors) discriminated initially favorable and unsure FDMs from initially unfavorable FDMs (1.491 and 1.051 vs. 0.132, respectively). Although less discriminating, FDMs with attitudes in domains A2 (aversion to changing body after death) discriminated initially unfavorable FDMs from initially unsure and favorable FDMs (1.812 vs. 0.645 and 0.402, respectively) and B3 (anti-donation behaviors) discriminated initially unsure FDMs from initially unfavorable and favorable FDMs (2.146 vs. 1.356 and 0.350, respectively).

Table 19

Classification Function Coefficients Indicated by Discriminant Function Analysis

Attitude Domain	FDM Initial Response Group		
	Favorable	Unsure	Unfavorable
A1: Donation invokes positive emotion	2.712	0.845	0.528
A2: Aversion to changing body after death	0.402	0.645	1.812
B2: Pro-donation behaviors	1.491	1.051	0.132
B3: Anti-donation behaviors	0.350	2.146	1.356

Specific Aim 3: Develop a suggestion for an educational intervention to change the public's understanding of and attitudes toward tissue donation

Interviews with TRs included an exploration of an educational intervention. The factors contributing to FDMs' attitudes are grouped into 2 overarching categories and are discussed below as they contributed to the suggested educational intervention: 1) FDMs' knowledge and attitudes and 2) other factors contributing to FDMs' attitudes. Following this is a discussion on TRs' strategies (i.e. counterarguments) to overcome FDM misconceptions and TRs' ideas for an educational intervention on tissue donation. The findings on FDMs' expressed attitudes toward tissue donation from Specific Aims 1 and 2 are expounded on and equally influence considerations for an educational intervention. Finally, a summary of the pros and cons of proposed interventions is discussed and the final suggestion is presented.

FDMs' knowledge and attitudes. TRs discussed different facets of FDMs' knowledge and how knowledge contributes to FDMs' attitudes. Coding of the semi-structured interviews with TRs displayed a relative consensus that families do not have a

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lot of knowledge about tissue donation. The frequencies for families' knowledge are shown in Table 20.

Table 20

TRs' Perceptions of Families' Knowledge about Tissue Donation

How much knowledge do families have about tissue donation?	<i>N</i> =14 <i>n</i> (%)
Families have more than some knowledge about tissue donation	1 (7.1)
Families have some knowledge about tissue donation	5 (35.7)
Families have very little knowledge about tissue donation	6 (42.9)
Families have no knowledge about tissue donation	2 (14.3)

More than half of TRs ($n=8$, 57.2%) felt that families have either very little or no knowledge of tissue donation. Likewise, only 1 TR (7.1%) felt that families have above average knowledge of tissue donation. As shown in Table 20, few TRs felt that FDMs have more than some knowledge about tissue donation. Since there is a lack of information about tissue donation for public consumption, FDMs who have these more informed attitudes may have developed them from either previous experiences of donating or receiving donated tissues, knowing others who have donated before, or through professional exposure working in the health care field.

In terms of the knowledge families lack, 8 (57.1%) TRs felt that families are not aware that tissue donation is even an option, 3 (21.4%) TRs felt that families do not understand the purpose or function of tissues, 1 (7.1%) TR felt that families do not know the types of gifts possible to donate, and 1 (7.1%) TR felt that families have trouble understanding the application of bone or skin grafts.

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Further, TRs described the statements families typically make that demonstrate confusion between tissue donation and organ donation. These statements and the frequency of TR endorsement are shown in Table 21. Seven (50%) TRs said confusion is because of a lack of education or knowledge, 3 (21.4%) said it's an automatic connection they can make, 3 (21.4%) said due to TV shows, movies, and/or media, and 1 (7.1%) said organ donation is easier to understand. Confusion between organs and tissues was a noteworthy trend among 27 (11.3%) FDMs in the study sample and corroborates with the earlier MANCOVA analysis which included this variable as one of two covariates.

Table 21

From the TRs' Perspective: Statements Families Make that Show Confusion between Tissue Donation and Organ Donation

What statement(s) suggest that families have confused tissues with organs?	N=14 n (%)
"[Patient] cannot donate tissues because s/he is already dead"	6 (42.9)
"[Patient] wasn't properly helped or medically treated because s/he was on the registry"	4 (28.6)
[Families will refer to specific organs] "...the heart/kidney..."	2 (14.3)
[Families will explain to others] "The request for tissues is about 'organ donation'"	2 (14.3)
"We want to meet the recipient(s)"	2 (14.3)
"The tissues are not suitable for donation since the organs were not suitable"	1 (7.1)

TRs indicated they have spoken with almost equal numbers of FDMs who associated tissues with organs in a positive way as in a negative way. In particular, the majority of TRs felt that the spillover attitudes from organ donation was negative ($n=5$, 35.7%), which was followed by TRs who felt it is both positive and negative ($n=4$, 28.6%), and then by TRs who felt that it is positive ($n=3$, 21.4%). One TR (7.1%) felt the spillover was neither positive nor negative and one TR (7.1%) did not respond to the question.

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Spillover attitudes seem to fall into 4 categories depending on whether the knowledge shaping these attitudes is true or false. Table 22, below, provides examples of spillover attitudes in the form of a contingency table, with positive and negative by true and false attitudes toward tissue donation.

Table 22

Positive/Negative x True/False Types of Spillover on FDMs' Attitudes

	True	False
Positive	Tissue donation is life-saving.	It is possible to meet the recipient(s) of tissues.
Negative	The tissue donation industry is profit-driven.	The patient will not receive enough medical attention because s/he is on the registry.

Other factors contributing to FDM attitudes. TRs spent a great deal of time discussing factors contributing to FDMs' attitudes including grief, cause of patient's death, media/TV/movies, experiences leading up to the tissue donation request, and outside opinions/attitudes. These factors are described below and derive from the TRs' perspective. While the following is descriptive, further investigation is needed to determine if any of these factors have statistically significant effects on FDMs' attitudes.

Grief. Five TRs referenced grief as a factor related FDMs' attitudes and their decisions to donate or refuse tissue donation. There are individual differences in terms of how FDMs grieve (i.e. do they go through all the stages of grief or just one?) as well as how quickly they grieve (ie. does it take an FDM 3 months to grieve or 1 hour?). Thus, TRs frequently stated that FDMs' attitudes toward tissue donation, along with other factors

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such as initial receptivity to tissue donation, often depend on where they are in the grieving process.

When families experience shock, TRs feel that the response towards tissue donation is often negative. One TR stated, "A lot of them are grieving. Back when I wasn't approaching the way I approach, I remember they were like 'Really? You're calling me right now to ask me for this stuff?! My mother just died. Really?!' So I think that some of it is like I'm already going through enough and now you want to take something from them."

Examples that TRs provided of FDMs' attitudes that are affected by grief included: the patient is suffering and will endure pain if tissues are procured, will be "cut on", and is still alive in some way. Yelling, blaming the patient's death on other parties (i.e. law enforcement, hospital, etc.), and hanging up the phone are behaviors that TRs said they have experienced. When asked specifically about the how this ties in with FDM initial response groups, TRs suggested that FDMs who are more favorable towards tissue donation are more receptive to the idea of tissue donation and better able to cope with the multitude of tasks surrounding a loved one's death. Readiness to deal with tasks might be associated with grief.

Time constraints placed on tissue donation requests further counteract TRs' efforts to support FDMs in making an informed decision about tissue donation. One TR summed it up as follows:

Sometimes we're on tight time constraints for tissue. Sometimes by the time we get the family's information, contact information, give them a little time to settle down, and call them we don't really have a lot of time to say ok I need to give them a little more time to try that I'll call and check on you in a couple of hours, you just don't

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have a couple of hours to waste. So time constraints are a little difficult in being able to respect their emotional position versus the need to educate them and get them ready to understand how important this is to say yes to donation. You're kind of playing on a very tight game with the clock ticking.

Cause of patient's death. TRs touched on the cause of the patient's death as an important factor affecting FDMs' attitudes. Causes of death include homicide, suicide, and natural causes. Along with cause of death is the expectedness of the death (i.e. did it happen suddenly or was there some indication beforehand?). TRs also discussed how FDMs of patients who were on life supports have different attitudes than those who were not. This may be explained by not only the cause of death, but by the type of death, such as brain death versus clinical death. Furthermore, TRs suggested that FDMs of patients who die of natural causes tend to have more favorable attitudes toward tissue donation than FDMs whose loved ones died of murder, for example.

Movies/Media/TV. Some TRs discussed the influence of media, television, and movies on FDMs' attitudes. Mostly, they described their negative impact on attitudes. One TR recalled a family say, "...there's a lot of people trying to hurry up and sneak in and grab your loved one's organs and then go sell it and profit off of it". When probed further, TRs explained that themes from movies seem to be that the donation industry is "sinister", "business-oriented", and "profit-driven". Horrific plots in movies from the 1970's and 1980's (i.e. the movie *Coma*) were referenced, which show doctors poisoning patients whose organs were good matches for bidders on the black market. FDMs often have graphic mental images of tissue donation in their minds from overly exaggerated scenes in movies or misrepresentations of the process. One TR said:

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A lot of families have that image of them being in a morgue or them being cut up like in a horror movie because a lot of times that's what they think and they don't realize that it's really in the OR and they're prepped and it's like a surgery and that we replace whatever we recover so that they would still be able to have a viewing and they'll still be able to say their goodbyes to their loved one.

In addition, stories in the media color the families' attitudes. For example, on MSNBC, a widely viewed story aired about funeral directors that also worked at a tissue bank in New Jersey who misrepresented patient records and robbed people's tissues. One TR said it was a "traumatic experience" not only for the FDMs but for her as well. TRs also discussed how FDMs make assumptions about the tissue donation process from television shows that feature organ donation. For example, FDMs often mistake how the consent process for tissue donation works, believing that paperwork for tissue donation is completed at the hospital the same way it is for organ donation. This logistical factor affects FDMs' attitudes, according to TRs. Another example referenced was from a current TV show called "Dead Like Me". In this show, the TR described grim-reapers taking the souls of deceased individuals and how those whose souls were taken after death can feel everything happening to their bodies. The only positive (although false) spillover attitudes from TV according to TRs is that they will get to meet the recipient(s) of the tissues.

Experiences leading up to tissue donation request. TRs discussed FDMs' experiences immediately prior to the tissue donation request. Examples TRs provided were experiences FDMs had at the hospital, negative feedback from a Funeral Director and/or the medical examiner's office or law enforcement. It seemed to the TRs that the

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closer in time these experiences were to the request, the more likely they were to influence FDMs' attitudes.

Outside opinions/attitudes. TRs also discussed the influence of others' opinions on FDMs' attitudes toward tissue donation. Examples provided of outside influences were doctors and nurses, friends, family members, and members of FDMs' religious congregation. FDMs are caught at such a vulnerable time, it is more difficult to challenge others' beliefs than to just go along with them. The literature on attitudes suggests that outside opinions/attitudes are potential root causes of the perseverance effect described earlier (Anderson, 1995; Anderson & Lindsay, 1998; Davies, 1997).

Counterarguments to overcome FDM misconceptions. While the factors described above create a challenging environment for TRs, they shared their strategies for overcoming such drawbacks. Past studies have shown that strategies such as persuasion and relational communication relate to FDMs decisions regarding tissue donation (Siminoff, Traino, and Gordon, 2011). Thus, TRs were asked what persuasive information or counterarguments they have provided FDMs with in order to attempt to change their misconceptions about tissue donation. Their responses were not mutually exclusive.

The counterarguments to overcome misconceptions in order of most to least frequently discussed were: explain how the patient's appearance will not be altered (64.3%), describe the recovery of tissues from the patient (50.0%), explain the difference between organ and tissue donation (50.0%), provide basic education (42.9%), share personal stories (35.7%), focus on the benefits of tissue donation for others (35.7%), explain the logistics of tissue donation (28.6%), ask the family to explain what they are

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thinking and why (21.4%), and refer to the patient being on the registry (14.3%).

Examples of these counterarguments can be found in Table 23.

Eight (57.1%) TRs thought the counterarguments work some of the time, 4 (28.6%) TRs thought they work often, and 1 (7.1%) TR said they always work. One (7.1%) TR reported s/he did not know if the counterarguments work.

Table 23

Examples of Counterarguments TRs Use to Overcome Misconceptions

Counterargument	Example(s)
	"There will not be any incisions to the face."
Explain how the patient's appearance will not be altered	"This is not whole limb donation."
Describe the recovery of tissues from the patient	"A thin layer of skin about the thickness of a sheet of paper will be taken from the backs of the arms and legs."
Explain the difference between organ and tissue donation	"While organs can help a few individuals, tissues from one donor can help up to 50 individuals."
Provide basic education	"Tissues, such as bones, can help people walk again."
Share personal stories	"I've been to an open casket funeral where the person who died was a tissue donor and I couldn't see any incisions."
Focus on the benefits of tissue donation for others	"The donation of corneas can help two people see as soon as two weeks after the donation." "Donated tissues can help veterans coming back from war."
Explain the logistics of tissue donation	"Everything will be done over the telephone."

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"We will make sure your loved one is transported to the funeral home."

Ask the family to explain what they are thinking and why

"Can you tell me what your concerns are?"

Refer to patient being on the registry

"Did you know that John is on the donor registry?"

Integrating the TR and FDM perspectives. Under Specific Aim 3, thus far, many factors contributing to FDMs' attitudes that TRs discussed during the interviews have been summarized above. To recap, most TRs (92.9%) felt that, in their experience of speaking with families, most FDMs only have some and mostly less than some knowledge of tissue donation. The main reason for a lack of knowledge according to 57% of TRs is that FDMs do not even know that tissue donation is an option after their loved ones have died. Related to the lack of knowledge is confusion between tissue donation and organ donation (or between tissues and organs). The most common statement made by FDMs that has demonstrated confusion between tissue donation and organ donation, according to TRs, is that "the patient cannot donate tissues because s/he is dead already." In other words, this is the belief that tissues are like organs where the patient must be on life supports in order to donate. While this belief would certainly expose FDMs' lack of understanding of the differences between tissue donation and organ donation, it was not expressed by FDMs in any of the request conversations sampled for this study. More commonly, FDMs demonstrated confusion by interchanging the words tissues and organs, or by stating the name of an organ (i.e., 'the heart', 'the kidney') instead of a tissue. Thus, while FDMs'

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confusion between tissues and organs is clearly an important issue elicited by both TR and FDM perspectives, exactly what the confusion entails needs further investigation.

Other factors that TRs alluded to as influences on FDMs' attitudes were individual differences regarding grief, the patient's cause of death, the media, outside experiences, and outside opinions. These factors correspond with past organ donation research that have suggested similar factors (specifically, who raised the issue of tissue donation and outside information/experiences) to significantly affect organ donation decisions (Radecki & Jaccard, 1997; Siminoff, Traino, & Gordon, 2010). Most of these factors were not identified by the FDMs in the request conversations and might have only been expressed if explicitly asked about them. Outside opinions are the only factor that ties into the attitudes expressed by FDMs in this study. Specifically, 26 (10.8%) FDMs conveyed expressions of guilt in managing other family members' divergent opinions and the need to make a decision (a subdomain in (A3): donation invokes negative emotion). Finally, the counterargument to overcome FDMs' misconceptions about tissue donation that was most commonly cited by TRs (64.3%) was how the appearance of the patient's body will not be altered by donating tissues. This supports the earlier finding that the TR domain with the highest ranking in terms of frequency of endorsement is aversion to changing the patient's body after death. By comparison, this domain ranked 6th by FDMs. The incongruence of the TR and FDM perspectives over FDMs' concerns about the patient's appearance creates a challenge in transferring this information to an educational intervention.

What this means for an educational intervention. The insight from the TR and FDM perspectives not only shows a need for an educational intervention on tissue donation, but also highlights critical elements to incorporate or at least consider for

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suggested interventions. These key elements to include in an educational intervention, assessed in conjunction with the results from the quantitative analyses are described below.

Differentiate between tissue donation and organ donation. Given that many of the FDMs' expressed attitudes and false beliefs were derived from a lack of understanding and confusion between organ and tissue donation (e.g. false beliefs regarding eligibility, mistrust of medical industry), a distinction between organs and tissues and their processes is a critical part of any educational intervention. As TRs discussed, FDMs often believe they cannot donate tissues because their loved ones have already passed. This belief, often giving rise to negative attitudes, should be changed, along with the other commonly heard statements provided by TRs, to increase the public's knowledge and consequently also their attitudes toward tissue donation.

Capitalize on influential factors. TRs discussed a variety of factors that may influence FDMs attitudes, which parallels research on organ donation that has shown similar factors to affect FDMs' attitudes toward organ donation (e.g. Radecki & Jaccard, 1997; Siminoff, Traino, & Gordon, 2010). Though little, if any, research has investigated the effects of such factors (i.e. grief, media, outside opinions) on FDMs' attitudes toward tissue donation, the TRs' emphasis on their impact only strengthens the basic argument for an intervention targeting the public earlier than at the time of a tissue donation request when a loved one has passed. The influence of others' opinions on FDMs' attitudes was specifically expressed by FDMs in this study's sample. Future research that uncovers the specific effects of these factors on attitudes can further hone an educational intervention.

TRs' perspective on public education about tissue donation. All TRs felt that educating the public about tissue donation would ultimately help to increase the consent rates. One TR summed it up as, "People have a lot of questions and misconceptions, and the only way to change that is education." Another TR explained that the public is only educated on how organ donation helps others: "They only see that organ, that kidney, is going to help someone else or that heart is going to help someone. They don't see how a bone can help someone or an Achilles tendon can help someone. That little kid who cannot walk now because his feet are like this, you know, he can walk again." The overwhelming consensus on the need for an educational intervention to increase awareness and understanding about tissue donation bolsters the rationale for Specific Aim 3.

Most TRs ($n=12$, 85.7%) feel there is not enough, if any, public education on tissue donation. The minimal public education they have seen includes local community events where the staff from LifeNet Health in Virginia Beach, Virginia give presentations; in some schools as an SOL requirement; or through celebrities on reality TV (namely, the *Real Housewives of New York*). Many TRs commented that they have not seen any public education outside of the tissue donation industry's local efforts and DMVs only provide brochures focusing mainly on organ donation. When renewing a driver's license at the DMV, the public is only asked if they want to sign up to be an "organ donor", usually not knowing this includes tissue donation as well.

Messages endorsed by TRs. TRs were asked about what they thought the most important messages to include in an educational intervention would be. The majority of TRs ($n=9$, 64.3%) felt that one of the most important messages would be that tissue donation is life-saving and/or life-enhancing, which was followed by the message of the

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number of individuals that one donor can help ($n=6$, 42.9%). Details of the messages TRs endorsed can be found in Table 24.

Thoughts about whether a message or educational intervention on tissue donation should be separate from organ donation were mixed, with about half of TRs feeling that organ and tissue donation should be kept together and the other half of TRs feeling that organ and tissue donation should be separated. When asked this same question later (at the presentation to be discussed below), TRs unanimously agreed that tissue donation should be separated from organ donation in an educational intervention.

Table 24

TRs' Suggestions for Messages to Include in an Educational Intervention for Tissue Donation

Most important message(s) to include in an educational intervention	<i>N</i> =14 <i>n</i> (%)
Tissue donation is life-saving/life-enhancing.	9 (64.3)
The number of individuals that one donor can help.	6 (42.9)
What the tissues can do.	5 (35.7)
Tissue donation improves health.	5 (35.7)
Tissue donation genuinely impacts lives (put a face with a story and situation)	4 (28.6)
Certain tissues can help people walk.	4 (28.6)
Tissue donation does not affect the appearance of your loved one.	3 (21.4)
Something good that can come out of something bad.	3 (21.4)
Cornea donation can help 2 people see in 2 weeks.	2 (14.3)
Tissue donation can give recipients the ability to hold someone.	2 (14.3)
The differences between organ and tissue donation.	2 (14.3)
Tissue donation allows you to leave the legacy of your loved one behind.	2 (14.3)
Statistics on the need for tissue donors (i.e. # of people waiting for tissues)	1 (7.1)
Any type of funeral service is still possible.	1 (7.1)
Donated tissues are used in ACL repairs for injured athletes.	1 (7.1)

Groups TRs would target in an educational intervention and reasons why. TRs

were asked what groups of people they would target in an educational intervention and

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why they would target those particular groups. The group that was most frequently cited by TRs ($n=7$, 50%) was the younger generation (<30 years) and was followed by ($n=3$, 21.4%) middle age individuals (30-60 years old). The other groups TRs said they would target included the older generation, Hispanic community, African American community, spouses, and children. Table 25 shows how many TRs endorsed each group that was discussed.

Table 25
TRs' Target Audiences for an Educational Intervention

Group	<i>N</i> =14* <i>n</i> (%)
Younger generation (<30 years old)	7 (50.0)
Middle age (30-60 years old)	3 (21.4)
Older generation (>60 years old)	2 (14.3)
Hispanic community	2 (14.3)
African American community	1 (7.1)
Spouses	1 (7.1)
Children	1 (7.1)

**Note. Frequencies do not add to 14 as TRs may have endorsed more than one group*

In addition, TRs discussed the reasons why they would target the groups they suggested for an educational intervention. Their reasons ranged from the misconceptions that are perpetuated by certain groups to a group's likelihood of being a decision-maker based on age or other characteristics. Their reasons are categorized by 6 themes: lack of knowledge, FDM characteristics, donor characteristics, number of donors, conduit of

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information, and in-group myth. The most commonly endorsed group, the younger generation, should be targeted in an educational intervention according to TRs because they lack knowledge, they comprise a large portion of registered donors, they are potentially the healthiest donors, and they are best suited for having discussions with family members. A matrix of this information is shown below in Table 26.

Table 26
TRs' Reasons for Targeting Suggested Audiences

	Audience to Target						
	Younger generation (<30)	Middle age (30-60)	Older generation (>60)	Hispanic community	African American community	Spouses	Children
Lack of knowledge	✓	✓	✓	✓	✓		
FDM characteristics	✓ Large portion of registered donors	✓ Majority of legal next-of-kin		✓ Language barrier	✓ Lack of trust in medical field/research	✓ <ul style="list-style-type: none"> Likely to follow through with loved one's wishes Experience most despair 	
Donor characteristics	✓ Healthiest donors						
Number of donors			✓ Largest group of actual tissue donors				
Conduit of information	✓ Best suited for discussions with family members						✓ Receptive to new info
In-group myth			✓ Too old to donate tissues	✓ <ul style="list-style-type: none"> Bodies more valuable dead than alive Organ donation industry is all profit-driven 	✓ <ul style="list-style-type: none"> Bodies more valuable dead than alive Tissues will not be allocated fairly 		

Suggestions for an educational intervention. The preliminary results from Specific Aim 2 were presented to the TRs at LifeNet Health and provided an empirical basis to obtain feedback for educational intervention suggestions. Below is a review of the suggestions that TRs presented and a brief discussion on the pros and cons of each suggestion based on past research and expert opinions. These ideas are listed in order of preference, from least to most preferable.

Fear appeals intervention. A TR discussed her experience with what she perceived to be an effective fear appeal intervention to educate and prevent teenagers from drunk driving. The intervention is called “Every 15 Minutes” for which she volunteered as a representative from LifeNet Health to talk to high school students about the grieving process following drunk driving-related deaths. This program has multiple scenes that students visit during school hours to experience the events and consequences of drunk driving. Examples of scenes include a mock car crash in the high school’s parking lot, a mock victim on a ventilator in the hospital, and a mock body at the morgue. The TR suggested that a representative from LifeNet Health speak to students about tissue donation and intervene at the morgue scene, like she did with donation in general at the hospital scene.

Pros. Since LifeNet Health is already connected to the program, it seems feasible for a representative to carve a niche at the morgue scene to discuss tissue donation. Bordin, Bumpus, and Hunt (2003) found that 1651 students who participated as the “living dead” (i.e. mock injured victims, deceased, or drunk drivers) were significantly more likely to drink less, speak more to their friends more about drinking and driving, and were less likely to drive after drinking or ride with someone who was drinking after a 57-day interval

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and a 218-day interval ($p's < 0.05$). In addition, the students' parents were more likely to discuss drinking and driving with their children, felt more prepared to deal with alcohol-related behaviors, and felt more confident that their child would not drink and drive ($p's < 0.05$).

Cons. This option might be more convincing to use in this situation if attitude domains such as "false beliefs regarding eligibility" or "negative physical changes" were more widely expressed by FDMs. The only study found, by Bordin, Bumpus, and Hunt (2003), lacks an experimental design, and thus, does not demonstrate the program's effectiveness. Moreover, only a select group of students were surveyed (i.e. those who participated as the "living dead"); surveys were not given to the majority of students participating in the program (i.e. those who viewed the scenes and were peripherally engaged in the intervention). In addition, a meta-analysis on fear appeals suggests that fear appeals are only effective when they include measures to increase self-efficacy (Witte & Allen, 2000). One study on educational messages and delivery suggest that positive messages are, by and large, more effective than scary or fear-provoking messages (Job, 1988). Finally, there are ethical issues to be considered when using fear appeals in any intervention.

Engaging the public at the DMV. TRs suggested educating people about tissue donation while they are waiting on line at the DMV. Since many DMVs have waiting times of 30 minutes or more, the opportunity to educate people about tissue donation exists, whether it be through a TV spot, a video, or a poster in plain sight.

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Pros. This approach would target a large portion of the public, specifically those that are over the legal driving age and who drive. At the DMV, the public would be a captive audience for learning about tissue donation.

Cons. Organ and tissue donation researchers have intervened at DMVs by educating the clerks about donation in general, but the long-term effectiveness has been questionable (e.g., Harrison, Morgan & Di Corcia, 2008). Moreover, bioethicists Whyte, Selinger, Caplan, and Sadowski (2012) suggest that educating people while they are angry from waiting on line at the DMV is not the best time or place for intervening. These authors suggest that an educational intervention feed off of people's altruistic nature, which is less accessible in the DMV setting. It makes sense to heed their advice as altruism is a part of the most highly endorsed attitude domain by family decision-makers in this study (e.g. "donation is valuable", a domain that represents FDMs' statements about wanting to help others in need). Further, Rodrigue and colleagues (2012) implemented an organ donation intervention at 15 DMVs in Florida and compared them to 15 DMVs that did not have the intervention. They did not find any statically significant differences between the intervention and control groups 8 months after the intervention took place ($p=0.13$) (Rodrigue, Krouse, Carroll, Giery, Fraga, & Edwards, 2012).

Nursing staff/funeral home directors. Two TRs discussed how some of the nursing staff and funeral home directors they work with, who are anti-donation, influence the attitudes of families. These TRs said they hear from families that they are not interested in donating because a nurse or funeral home director spoke with them and changed their minds. An intervention educating these two groups was recommended.

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Pros. Past studies on the attitudes, knowledge, and behavior of healthcare professionals towards tissue donation have been conducted. Kent and Owen (1995), for example, suggest that the lower rate of corneal donation compared to other donations is likely due to nurses' conflicting attitudes with the donor families. Further, Lin, Lin, Lam, and Chen (2010) found that ICU nurses had a significant increase in knowledge and gained more positive attitudes toward organ donation after receiving educational training on the topic of organ donation ($p's < 0.001$). In addition, LifeNet Health TRs shared anecdotes about their increased efforts with improving communications with funeral directors in their area and said they have seen improvements over the years.

Cons. While funeral home directors and nurses certainly may influence families' attitudes toward tissue donation, the findings from this study indicate that the public's attitudes are often formed before coming into contact with these individuals. The purpose of an educational intervention would be to educate the public in an objective way prior to this so that they can make informed decisions about tissue donation.

Have children educate parents and families. One TR discussed the impact that car safety campaigns have had on society, particularly those that started at the school level. In the past, public health educators have shared the importance of wearing a seatbelt when driving to children at their schools. Children went home and told their parents that they had to wear their seatbelts and shared the possible consequences of not engaging in this behavior. Since then, seatbelt use has become commonplace. This TR explained that developing a message about tissue donation to give to children that they can then share with their parents and families might be effective, based on the effectiveness this method had on car safety.

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Pros. Due to efforts in school-based programs to promote the use of seatbelts for car safety, seatbelt use has risen steadily over the years in the United States. Campaigns that educate children with the intention of also educating and bringing greater awareness parents seems to fall in line with the findings above where TRs expressed that they think the younger generation is not only most receptive to information, but also best suited to relay information to their parents.

Cons. Tissue donation may be a more complicated topic to educate children on than seatbelt use. Also, since tissue donation doesn't necessarily impact children in the near future, health behavior theories (i.e., Theory of Planned Behavior or Information-Motivation-Behavioral Skills Model) suggest that an educational intervention targeting children in schools will not be as effective (Ajzen, 1991; Fisher & Fisher, 1996).

Famous endorsers and life-enhancing messages. Many TRs agreed that having sports stars, actors/actresses, and celebrities endorsing tissue donation would be the quickest and best way to publicize tissue donation. Messages they could endorse include, "Let me show you the heart on my license" and explain that it includes tissue donation; "Look how tissue donation changed my life. I'm able to keep [insert activity here; e.g. dancing, playing football, running, playing piano];" and, "Now it's time to pay it forward by signing up to be a tissue donor."

Pros. Including celebrities as endorsers of organ donation has been successful in the past. For example, in the 1990s Coalition on Donation ran an ad campaign about the importance of organ and tissue donation that featured basketball star Michael Jordan. This campaign received a great deal of attention, though, to this researcher's knowledge, no research on its effectiveness has been conducted.

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Cons. While famous icons have the potential to draw a lot of appeal towards tissue donation, this would be a very costly option. Also, it's possible that the educational part on tissue donation would get lost with the focus being on the celebrity.

Facebook campaign. The topic most discussed by TRs was the use of social media, in particular of Facebook, to change the attitudes of the nation's youth. In May 2012, Facebook launched an organ donation campaign whereby users can add their donation status to their timelines. Once a user enters this module, Facebook automatically directs him/her to Donate Life America's registration page. This campaign to increase organ donor registration went viral, increasing the numbers of people who signed up to be donors in almost every state.

Pros. Facebook reaches millions of users worldwide and has the potential to reach non-users simply through discussions between users and non-users. An educational intervention or campaign using Facebook capitalizes on people's altruistic nature by hopefully touching those who are "others-oriented" through the dissemination of information about how tissue donation improves the lives of others. This is coupled with furnishing public recognition to those who register. A "life event" for tissue donation similar to that of organ donation is likely to follow a similar trend in terms of increased registration rates and greater awareness about donation.

Cons. An educational intervention utilizing social media may not reach older adults, people of lower SES or those who live in rural areas. Working with the staff of Facebook and getting them on board to include a module for tissue donation may be challenging.

Integrating the suggestions into a final intervention recommendation. After weighing the pros and cons of each of the ideas suggested by TRs, as well as incorporating

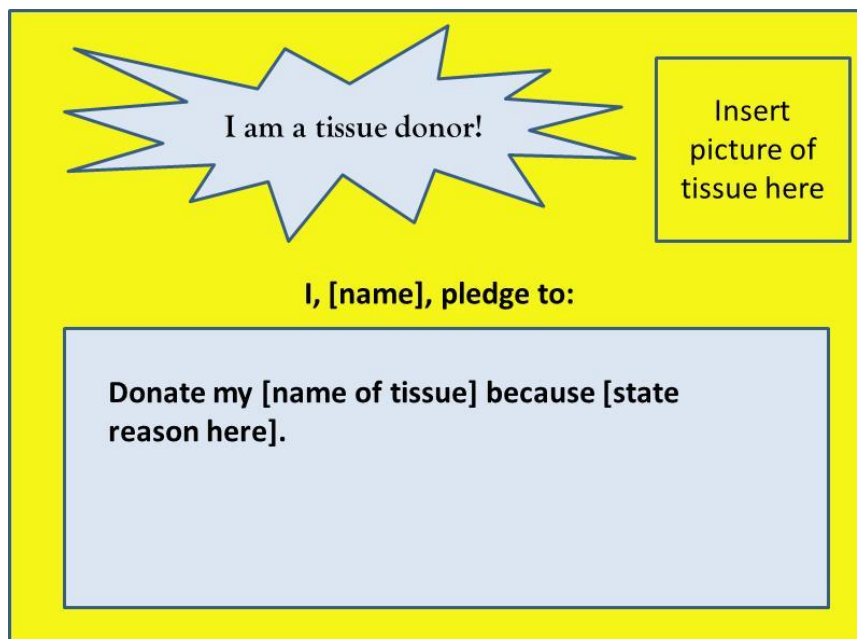
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some of the findings from both the TR and FDM perspectives, a visual representation of a module to be implemented on Facebook is provided below. Under the “Life Events” tab on Facebook under one’s profile, the user would have the ability to enter his/her registration information for tissue donation. The screen below would appear on that user’s timeline and on his/her newsfeed for the public to see (unless there are privacy settings restricting this from being seen by others). The idea is for this message to have a chain reaction effect whereby one person that registers and uses this module brings awareness to several hundred people in their circle(s) and causes others to follow suit. In the process, members of the public are educated about the tissues that can be donated and what they are used for in the explanation box in light blue. Users would have the options of choosing an explanation from a drop down menu or the ability to write in their own reasons for donating. Either way, the explanation section will create more awareness and educate the public about tissue donation. This suggestion taps into the behavioral attitudes of the public’s attitudes, which were found to discriminate between the three FDM groups in the first discriminant function analysis. More specifically, the two attitude domains that best discriminated FDM group membership in the second discriminant analysis, donation invokes positive emotion (A1) and pro-donation behaviors (B2), are tapped into for this suggested intervention. Since FDMs who were initially favorable towards tissue donation expressed significantly more attitudes in these two domains than their counterparts (FDMs that were initially unsure and unfavorable), the hope is that this educational intervention ignites discussion and at least initial favorability towards tissue donation.

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Figure 2

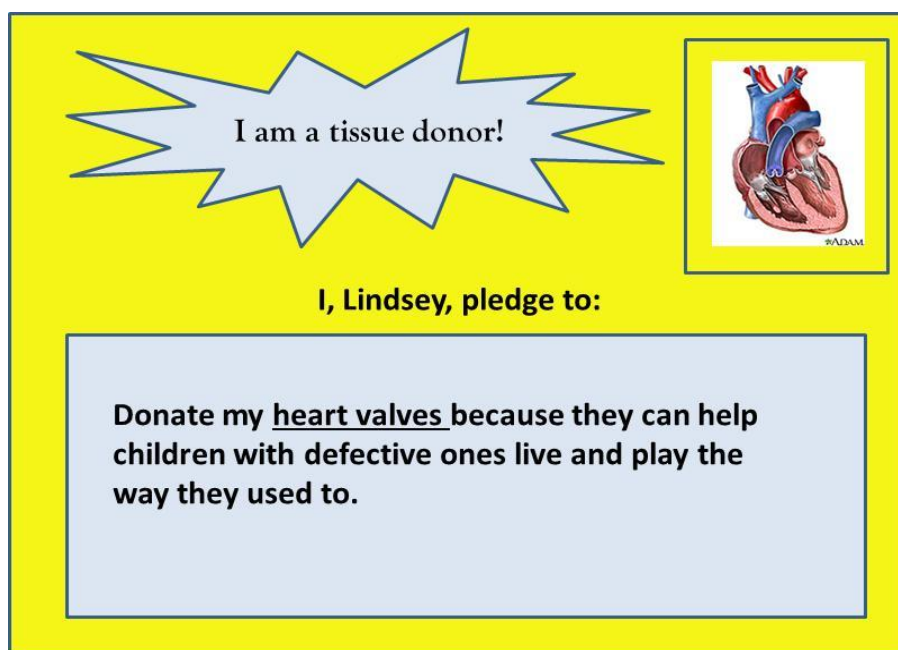
Template of Tissue Donation Module on Facebook



A yellow rectangular template for a Facebook post. At the top left, a blue starburst shape contains the text "I am a tissue donor!". To its right is a small white box with a black border containing the text "Insert picture of tissue here". Below the starburst, the text "I, [name], pledge to:" is centered. Underneath this is a large light blue rectangular box containing the text "Donate my [name of tissue] because [state reason here].".

Figure 3

Example of Completed Tissue Donation Module



A completed version of the yellow rectangular template. The blue starburst at the top left contains the text "I am a tissue donor!". To its right is a small white box with a black border containing a medical illustration of a human heart with blue and red vessels, and the text "#ADAM" at the bottom right. Below the starburst, the text "I, Lindsey, pledge to:" is centered. Underneath this is a large light blue rectangular box containing the text "Donate my heart valves because they can help children with defective ones live and play the way they used to."

Chapter VI. Discussion

Many of the findings from this study not only use a subset of data from prior research, but also build off of the findings from such research on tissue donation. For example, Siminoff, Traino, and Gordon (2010) found that tissue donation consent is associated with FDMs' initial reactions to the donation request, such that those with initially more favorable attitudes towards tissue donation are more likely to consent to donation than those whose initial attitudes are unfavorable. This pivotal finding established the framework for the present research study. Below, implications of the study's findings as well as the limitations and suggestions for future research are discussed.

Congruence of TR and FDM Perspectives

It is notable that TRs' perceptions of FDMs' attitudes based on their experiences of speaking with families were very similar to the expressed attitudes of FDMs. While there were notable differences between the two, for example, TRs' endorsing appearance attitude domains more frequently than they were actually expressed by FDMs, it is possible that we would see more concordance if our sample consisted of more recent requests. As attitudes are often influenced by culture of the times, recent negative media on tissue donation over the past decade certainly may impact the public's attitudes. Future studies should investigate this phenomenon analyzing more recent tissue donation requests. Along the same lines, the TRs interviewed for this study have received more rigorous and comprehensive skills-training for requests and so it makes sense that their perceptions don't perfectly match up to FDMs' expressed attitudes. Also, future studies should attempt to interview more TRs than this study could feasibly gather.

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It was interesting to note the domains and subdomains that were incongruent between TRs and FDMs, as there are implications for how TRs can address some of the more seemingly important issues (i.e., money) and omit others (i.e., the way the patient will literally feel after tissues are procured) during their future requests with FDMs.

FDM Attitude Domain Rankings

Interestingly, the FDM attitude domains that had a positive valence toward tissue donation were more frequently endorsed or expressed than the attitude domains that had a negative valence toward tissue donation. The domain rankings might provide insight into the order of attitudes expressed during tissue donation requests. For example, attitudes in domain A2 (aversion to changing body after death) were expressed more commonly and perhaps before those in domain C3 (curiosity about negative physical changes), and both were related to the appearance of the patient's body. The affective attitude domain was ranked higher than the cognitive attitude domain, indicating that perhaps affective attitudes influence a person's overall attitudes toward tissue donation more than cognitive attitudes. This is an interesting research question that may be addressed through step-wise regression analyses in future research studies.

FDM Sample

As expected, those with initially favorable attitudes toward tissue donation were more likely to be Caucasian, more willing to donate their own organs and tissues, and have their donor card or license marked for donation. These characteristics also mirror FDMs who donated organs (McNamara et al., 1999; Parisi & Katz, 1986; Siminoff, Gordon, Hewlett, & Arnold, 2001; Wakefield, Watts, Homewood, Meiser, & Siminoff, 2010). No significant differences were found for sex or age. While there being no differences for age is

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surprising, perhaps sex would be statistically significant if men were oversampled (as women made up about 70% of the sample).

Misconceptions and Attitude Formation

Coding of the audiorecordings of tissue donation requests revealed FDMs' confusion between organ and tissue donation. It makes sense that this confusion occurs as the majority of information, if any, about tissue donation that is retrieved prior to the request is about "organ donation" or about "organ and tissue donation". FDMs' misconceptions about tissue donation may come from numerous sources and may be influenced by how information about donation has been encoded and under what circumstances that information is received. FDMs' experiences and exposures to tissue donation, in combination with how they were encoded (positively or negatively), provides insight into how FDMs' attitudes were formed. If the experience or exposure was positive, attitudes will usually be positive or favorable towards tissue donation. If the experience or exposure was negative, attitudes will usually be negative or unfavorable towards tissue donation. This information-processing conceptualization, which highlights the encoding, storing and retrieval of information, is widely recognized in the field of cognitive psychology and might play a role in attitude formation (Chaiken & Trope, 1999; Dillard, 2002). Future studies should take this model into account as one of the many possible underlying mechanisms involved in the formation of attitudes towards tissue donation.

Analyses

A k-means cluster analysis revealed a cluster of FDMs with similar attitudes (i.e., the attitude domains they endorsed) and also highlighted a group who expressed no attitudes. The final cluster centers provided insight into the attitudes held by three groups of FDMs.

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While the behavioral and cognitive components mapped onto one of their respective attitude domains, the affective component did not, which suggests that the two non-affective domains within the “affect” cluster of FDMs (B2-pro-donation behaviors and C1-donation is valuable) were potentially misclassified conceptually through the coding and data reduction process. This explanation is plausible given that the 3 attitude domains endorsed by FDMs in the “affect” cluster were fairly similar in terms of attitude valence and content. It is possible that these 3 attitude domains together (A1-donation invokes positive emotion, B2-pro-donation behaviors, and C1-donation is valuable) can be considered one collective affective domain. If we consider the two non-affective domains in cluster 1 as affective, 5 out of 14 domains mapped onto the Tripartite Model of Attitude Structure, which means that FDMs’ attitudes, as classified by this set of domains, was only partially successful in corroborating attitude theory. It is also possible that the idea of affect versus cognition being two separate and distinguishable components is untrue.

It was surprising that none of the theory-driven covariates in the first MANCOVA (i.e. race, education, religion, FDM’s relationship to the patient and thought patient wanted to donate) were significant. The covariates for this model were selected a priori based on previous tissue donation research (Rodrigue, Scott, & Oppenheim, 2003; Siminoff, Traino, & Gordon, 2010) and organ donation research (Siminoff, Gordon, Hewlett, & Arnold, 2001; Wakefield, Watts, Homewood, Meiser, & Siminoff, 2010) that suggested there were significant relationships between these variables and donation decisions. A major difference, however, between past studies and this one, is the way in which attitudes were measured (attitude responses to surveys versus expressed attitudes). The MANOVA,

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analysis without these covariates, did a better job of explaining the differences in attitudes between the three FDMs.

Further, the first discriminant function analysis confirmed the findings of the MANOVA. However, unlike organ donation studies that have suggested that affective and cognitive components of attitudes are the most salient (Van Den Berg, Manstead, Van Der Pligt, & Wigboldus, 2005), behavioral attitudes best discriminated between FDM groups, or similarly, the FDM groups were most different for behavioral attitudes in this study. This finding sheds light on the importance of affective and behavioral attitudes in distinguishing initially favorable FDMs from initially unsure and unfavorable FDMs. Supporting this finding is the fact that the most endorsed attitude domain FDMs held was of the behavioral attitude component (patient's wishes). The final suggestion for an educational intervention targeted the behavioral attitudes, in particular, expressing one's wishes regarding tissue donation to family and friends.

Educational Intervention for Tissue Donation

The TRs interviewed discussed groups they would target with an educational intervention. The matrix detailing the information they shared (Table 26) may prove useful for future researchers utilizing audience segmentation to target specific groups of the public with an educational intervention. On a similar note, although the racial and ethnic backgrounds of FDMs in this study is fairly representative of that in the United States, future studies may want to oversample racial and ethnic minorities in order to obtain a clearer picture of their attitudes and beliefs when developing an intervention.

The suggestions from TRs on educational interventions varied widely. The final suggestion, the Facebook module, requires permission from Facebook to implement. Based

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on reports of the organ donation Facebook module showing a drastic decrease in donor registrations after about a month of implementation (Sadler and Sadler, 2012), it will be necessary to have continual cues or reminders to ensure its long-term effects on the public's attitudes and designation rates. Prior to implementing any intervention, formative research needs to take place with a representative sample of the public, perhaps through focus groups, to confirm the assumptions that have been made regarding people's attitudes toward tissue donation. Additionally, research is needed on the attitudes of potential end-users of Facebook and their thoughts on their uptake of this intervention.

The hope is for this idea to eventually translate from science to practice. Similar to how Donate Life of America formed a partnership with Facebook for the organ donation campaign, it will be necessary to form a partnership with an organization of similar stature to promote tissue donation. Due to the discernible need to educate the public about tissue donation independently from organ donation and Donate Life of America's strong focus on organ donation, it is important to appeal to organizations that focus solely on tissue donation, such as AATB or EBAA (Eye Bank Association of America). As the types and uses of tissue donation are vast, and perhaps more complex than organ donation, perhaps forming a partnership with EBAA, which focuses solely on eye/corneal donation, would be beneficial for the public. It would also help EBAA meet and support the IAPB's (International Agency for the Prevention of Blindness) international goal to increase corneal donations. Its recent campaign is "Vision 2020: The Right to Sight".

Intervention for TRs

From a practice standpoint, the findings herein may prove useful to TRs at LifeNet Health as well as tissue donation staff at other OPOs. By knowing which attitude domains

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typically belong to FDMs with certain initial responses or levels of favorability towards tissue donation, TRs may be able to actively address families' concerns and possibly modify attitudes during requests. For example, since aversion to physical changes to the patient's body after death discriminates initially unfavorable FDMs from favorable FDMs, TRs can address appearance issues with FDMs if they are initially unfavorable. The findings from this study indicate that TRs should focus more of their attention on the behavioral component of FDMs' attitudes (such as, addressing issues surrounding the patient's wishes) as it was the most frequently endorsed component by FDMs and is highly predictive of FDM group membership. Moreover, since concerns about money may inhibit families from donating, it is important to include training about this information in a future communication intervention devised for TRs.

Public Policy Implications

The creation of an enforceable first person consent law for tissue donation combined with a more explicit and widely used portal for tissue donation designation has far-reaching implications for public policy. In addition, hospital development and communication with OPOs/tissue banks have the potential to raise awareness about tissue donation and increase donor registrations and ultimately tissue donation consent rates. These implications are discussed below.

First person consent for tissue donation. As stated earlier, public education on tissue donation has been neglected. Although first person consent laws provide for binding donation decisions, the reality is much different for tissue donation as compared to organ donation decisions. Despite first person consent laws, TRs routinely approach FDMs to donate their loved ones' tissues because they realize that the public is largely unaware that

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their designation as a donor extends to tissue donation. Public education about tissue donation could have a major effect on tissue donation policies. If there is an increase in public education on tissue donation (i.e., through the Facebook module recommendation described earlier, as one example), and if empirical evidence shows an increase in the public's knowledge about tissue donation, it may then be possible for OPOs and Tissue Banks to extend the practice of informing rather than requesting donation from families of designated donors. The implication is that first person consent for tissues will be binding just as it is for organs.

An explicit "tissue donor" designation. Another related but separate issue that has policy implications includes creating a clearer way of identifying oneself as a tissue donor. Since the majority of people register to become donors at their local DMVs, and their wishes are solely indicated on their drivers' licenses with a heart or "organ donor" label, it may be most effective to intervene at the DMV. It is very difficult, if not impossible, to discern whether a person wishes to be a tissue donor from the current method of designation at the DMV. Perhaps another label saying "tissue donor" could be added to drivers' licenses. In addition, although less frequently used, many states have online registries, which could be accessed through the Donate Life of America website and include specific options or boxes to check for tissue donation (i.e., which specific tissues you would like to donate). Perhaps DMVs could provide kiosks with computers linking individuals to these registries. If this becomes a standard procedure for designating oneself as a donor, patients' wishes will be more clearly designated.

Hospital development. The National Organ Transplant Act requires OPOs to assist hospitals in developing protocols for making routine inquiries about organ donation by

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potential donors (DHHS-OIG, 2001). The same assistance to hospitals about tissue donation should be required for tissue banks. Several studies (i.e., Rodrigue et al., 2003 & Siminoff et al., 2010) have found that families are often very surprised to receive a phone call and receive information about tissue donation immediately after their loved ones' death. Tissue banks providing more information to families at hospitals can improve initial responses to tissue donation and allow more time to make an informed decision about donation. Public education at hospitals is particularly important for families whose loved ones have not designated themselves as donors. For other families, information about tissue donation could catalyze discussions with other family members, so that their wishes become known. Information may be easily disseminated through an educational brochure that is structured around addressing negative attitudes as reported in this study, that families are likely to have. In addition, this study indicates that an educational brochure should also include appeals to altruism. Hospital development will contribute to a greater awareness about tissue donation.

Study Limitations

This study is the first to investigate the expressed attitudes individuals hold towards tissue donation and advances the attitude research on tissue donation by more holistically measuring attitudes as they are expressed, and not forced by a limited and closed-ended attitude scale on an administered questionnaire. However, there are some limitations that should be noted. The dependent variables, the 14 attitude domains, were dummy coded in order to conduct chi squared and t-tests for the relationships between variables as well as for the cluster analysis. While significant differences were found for many of the study variables, it is important to interpret these potentially inflated findings with caution. An

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observed “lack of attitude expression” is different than an explicit “no” response to a survey or interview question, which would be represented in an analysis the same way. This is a common limitation when analyzing qualitative data.

A surprising number of FDMs expressed positive attitudes despite being initially unfavorable and ultimately refusing to donate tissues. It is possible for FDMs to have different underlying attitudes than what are expressed as well as having a mixture of positive and negative attitudes towards an attitude object at the same time. The only way to measure the underlying attitudes might be through an Implicit Association Test, which evaluates the strength of an individual's unconscious relationships between objects or beliefs (Greenwald, McGhee, & Schwartz, 1998). In addition, many FDMs do not verbally or explicitly express their attitudes during the request. This could be due to any number of reasons. Secondary findings from the coding of requests, not reported earlier, indicated on several occasions that FDMs expressed they were too emotional, overwhelmed, or tired to talk, which are plausible explanations for a lack of attitude expression. Additionally, and possibly more likely, attitudes were not expressed in half of the requests because they were not explicitly asked for during the call. The attitudes for these FDMs are thus not captured through the qualitative coding method used in this study. Though inter-coder reliability was over 90%, it is possible, as with any qualitative coding scheme, that a different researcher or different set of coders may have conceptualized or coded the expressed attitudes of FDMs differently. Replications of the study are needed in order to corroborate these findings.

Future Research

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On a more macro level, the attitudes expressed in this study may not directly reflect those held by the public at large. Though the FDMs represent people of diverse backgrounds, they may have different attitudes than the general public as their attitudes are assessed during an emotionally compromised time, following the death of a loved one. Future researchers of tissue donation should not only sample members of the general public who are not tasked with making an imminent decision about tissue donation, but should also compare members of the general public to grieving FDMs to see if there are any statistically significant differences in their attitudes. A potential shortcoming of surveying members of the public, however, would be social desirability bias. It is important to keep in mind the strengths and weaknesses of either approach in measuring the public's attitudes toward tissue donation.

Finally, although it is a widely accepted model, the Tripartite Model of Attitude Structure is not foolproof or absolute. Attitudes may not always be placed into a distinct category, affective, behavioral, or cognitive, as they can justifiably have more than one attitude component. Future studies should more closely examine the interactions between FDMs' attitude components using grounded theory to determine if the Tripartite Model of Attitude Structure is how attitudes towards tissue donation are best conceptualized.

Conclusion

The exploration of FDMs' attitudes led to a greater understanding of the formation of attitudes towards tissue donation, accomplishing Specific Aim 1. The attitude domains and subdomains, from the perspectives of TRs perceptions of FDMs' attitudes and FDMs' expressed attitudes, were used in the analyses for Specific Aim 2 to assess the attitude

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differences among FDM initial response groups. While there were some similarities between FDMs attitudes toward tissue donation and toward organ donation, some differences were also found. In general, the Tripartite Model of Attitude Structure held up well in this context and should be considered as a theoretical framework for future research on attitudes towards tissue donation. FDM groups differed in terms of their expressed affective, behavioral, and cognitive attitudes, with behavioral attitudes best able to discriminate between them. Specifically, pro-donation behaviors and attitudes involving positive emotion differentiate initially favorable FDMs from initially unsure and unfavorable FDMs. Knowledge of the differences among FDM groups in terms of their attitudes led to Specific Aim 3, to develop an idea for an educational intervention about tissue donation. After integrating the findings and feedback from TRs at LifeNet Health about suggestions for an educational intervention, a final idea was presented. Any future educational interventions should target behavioral attitudes in general, and pro-donation behaviors and positive affect towards tissue donation more specifically, depending on the type of intervention and the target audience. Understanding the public's attitudes toward tissue donation is the first of many steps to increase the public's awareness and knowledge about tissue donation as well as to dispel pervasive myths and misconceptions, with the ultimate goal of increasing tissue donation consent rates in the United States.

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Appendices

- A. Tissue Requester Interview Guide
- B. Tissue Requester Coding Instrument
- C. Tissue Requester Coding Manual
- D. Family Decision-Maker Coding Instrument
- E. Family Decision-Maker Coding Manual

Appendix A

Tissue Requester Interview Guide

Introduction:

Thank you again for agreeing to participate in this interview. We are interested in learning about the attitudes and knowledge that are expressed by family decision-makers of deceased patients with whom you discuss tissue donation. I'm going to begin by asking you about your perceptions of family decision-makers' knowledge and attitudes toward tissue donation.

Tissue Requesters' Perceptions of Family Decision-Makers' Knowledge and Attitudes

1. In the course of speaking with families, you must hear many different things about tissue donation. Could you tell me how much or little knowledge people have about tissue donation?
2. What kinds of attitudes are expressed by families about tissue donation? (PROBES: Do people have attitudes that are based in an emotional response to the idea of tissue donation? A lot of times people base their attitudes on what they think about tissue donation but there isn't a lot of information out there. What information is based on facts that may be correct or incorrect? What attitudes do you think are a spill-over from organ donation? Do you think people's attitudes toward tissue donation are affected by a family member or the patient having a donor card?)
3. Now I'd like you to focus on some of the misconceptions you hear. What kinds of misconceptions are most common? How do you overcome these? Do these strategies work? (PROBE: Do their attitudes change when you employ these strategies? Do they still hold on to those beliefs?)
4. We've talked a lot about people's general knowledge and attitudes toward tissue donation. Now I want to talk about your experience. In general, can you tell me about your observations of families' initial reactions to the request for tissue donation in terms of a range of or common responses you encounter?
5. More specifically, what are some of the things said or issues brought up by families who are initially...
 - a. Favorable toward tissue donation? (PROBE: Which issues stand out the most? Why?)
 - b. Unsure or undecided about tissue donation? (PROBE: Which issues stand out the most? Why?)
 - c. Unfavorable toward tissue donation? (PROBE: Which issues stand out the most? Why?)

Keeping in mind your knowledge of family decision-makers' knowledge and attitudes toward tissue donation, I'd like to get your thoughts and opinions regarding an educational intervention for the general public.

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Tissue Requesters' Ideas for an Educational Intervention

6. Do you see much public education on tissue donation? (PROBE: What do you see?)
7. What do you think would be the most important messages to include in an educational intervention about tissue donation for the general public?
 - a. Is there any particular group you would target? Why?
8. Do you think educating the public about tissue donation would help to increase consent rates?
 - o Yes
 - o No
 - o Not sure/Undecided
 - a. Why or why not?

Thank you so much for your time. We hope that the information you have given us will help us understand the attitudes of family decision-makers and inform an educational intervention to increase consent rates for tissue donation. After I incorporate your responses in this interview into an instrument to code family decision-makers' attitudes in a sample of requests on audiotapes, I will return to LifeNet to get some requesters' thoughts and opinions about the instrument. This will only take approximately 15 minutes of your time. Would you be interested in participating?

Also there may be things that come up later or questions regarding your responses to this interview. Can I call you to follow-up on any questions that may arise?

Appendix B

Entered By:
Date Entered:

Case #:	
Coder's Initials:	
Date Coded:	

LifeNet Health Tissue Requester Coding Instrument

1. How much knowledge do families have about tissue donation?

- 1 ☐ Families have no knowledge about tissue donation
- 2 ☐ Families have very little knowledge about tissue donation
- 3 ☐ Families have some knowledge about tissue donation
- 4 ☐ Families have more than some knowledge about tissue donation
- 5 ☐ Families have a lot of knowledge about tissue donation
- 6 ☐ Don't know
- 7 ☐ NR/NA

2. What knowledge about tissue donation do families have?

- 1 ☐ Families think that tissue donation is like organ donation
- 2 ☐ Families are familiar with heart valves and eyes
- 3 ☐ Families' knowledge comes from knowing someone that has been a recipient of tissue donation
- 4 ☐ Families have no knowledge about tissue donation
- 5 ☐ Don't know
- 6 ☐ NR/NA

3. What knowledge do families lack?

- 1 ☐ Families are not aware that tissue donation is an option
- 2 ☐ Families don't understand the purpose/function of tissues
- 3 ☐ Families don't know the types of tissues possible to donate
- 4 ☐ Families have trouble understanding the application of bone/skin grafts
- 5 ☐ Don't know
- 6 ☐ NR/NA

4. What are some of the affective attitudes families have?

A. Positive:

- 1A ☐ Families are excited

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- 2A ☐ Families feel good
- 3A ☐ Families feel grateful
- 4A ☐ Other _____
- 5A ☐ Don't know
- 6A ☐ NR/NA

B. Negative:

- 1B ☐ Families feel guilty
- 2B ☐ Families experience the "ick factor"
- 3B ☐ Families feel that tissue donation is barbaric
- 4B ☐ Families feel that tissue donation is offensive
- 5B ☐ Families feel that request too difficult to understand at raw moment in life
- 6B ☐ Families do not want patient's body to be touched
- 7B ☐ Families do not want patient's body to be cut on
- 8B ☐ Family has been through enough already
- 9B ☐ Families feel that the patient has been through enough already
- 10B ☐ Families want to remember patient the way s/he was
- 11B ☐ Families feel the details of tissue donation not important
- 12B ☐ Tissue donation conjures negative imagery
- 13B ☐ Families feel that donating tissues is going too far
- 14B ☐ Other _____
- 15B ☐ Don't know
- 16B ☐ NR/NA

5. What are some of the behavioral attitudes families have?

A. Positive:

- 1A ☐ Families are registered donors
- 2A ☐ Families supports patient's wishes
- 3A ☐ Families had a discussion about donation with patient
- 4A ☐ Families told patient tissue donation was a good thing to do
- 5A ☐ Families have discussed donation with family
- 6A ☐ Families have discussed donation with friends
- 7A ☐ Families have discussed donation with others
- 8A ☐ Families have donated before
- 9A ☐ Families are involved with donation in some way (Specify how: _____)
- 10A ☐ Other _____
- 11A ☐ Don't know
- 12A ☐ NR/NA

B. Negative:

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- 1B ☐ Families told patient tissue donation was NOT a good thing to do
- 2B ☐ Families are NOT registered donors
- 3B ☐ Families do NOT support patient's wishes
- 4B ☐ Families have discussed donation with family
- 5B ☐ Families have discussed donation with friends
- 6B ☐ Families have discussed donation with others
- 7B ☐ Other _____
- 8B ☐ Don't know
- 9B ☐ NR/NA

6. What are some of the cognitive attitudes families have?

A. Positive:

- 1A ☐ Families believe it's the right thing to do
- 2A ☐ Families believe it's better the tissue is used than unused
- 3A ☐ Families believe that patient is just a body, not a person
- 4A ☐ Families believe tissue donation saves lives
- 5A ☐ Families believe tissue donation helps people
- 6A ☐ Other _____
- 7A ☐ Don't know
- 8A ☐ NR/NA

B. Negative:

- 1B ☐ Families believe donation will alter patient's appearance
- 2B ☐ Families believe there will be nothing left of patient
- 3B ☐ Families believe patient is still alive in some way
- 4B ☐ Families believe tissue donation will delay the funeral
- 5B ☐ Families believe tissue donation will affect the viewing
- 6B ☐ Families believe patient's body will not be treated with respect
- 7B ☐ Families believe that patient's tissues are not suitable for donation
- 8B ☐ Families believe that tissue donation will cost him/her money
- 9B ☐ Families believe that tissue donation is only possible with cremation
- 10B ☐ Families think they have to go to the hospital to donate patient's tissues
- 11B ☐ Families believe that the patient will not be able to be buried
- 12B ☐ Families think that not enough medical attention will be provided to patient
- 13B ☐ Families think patient is too sick to donate/has too many medical conditions
- 14B ☐ Families think that rich people get organs/tissues faster
- 15B ☐ Families believe that patient's body parts will be taken
- 16B ☐ Families believe tissue donation does NOT save lives
- 17B ☐ Families believe tissue donation industry is all profit-driven
- 18B ☐ Families believe tissue donation industry is sinister and manipulative
- 19B ☐ Families believe tissue donation is not possible because patient is dead

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- 20B ☐ Families believe tissues will be wasted
- 21B ☐ Families think patient is too old to be on registry/donate
- 22B ☐ Families believe they will not be able to see patient again
- 23B ☐ Families think the patient will not feel the same
- 24B ☐ Families think the patient will not look the same
- 25B ☐ Families believe the patient wanted to go out of the world the way he came into it
- 26B ☐ Families want the patient to go out of the world the way he came into it
- 27B ☐ Families think it's against patient's religion
- 28B ☐ Families think it's against their religion
- 29B ☐ Families believe the eyes are the windows to the soul
- 30B ☐ Families believe the patient needs all his/her parts to get into heaven
- 31B ☐ Families think the patient's tissues will not do any good
- 32B ☐ Other _____
- 33B ☐ Don't know
- 34B ☐ NR/NA

7. Families' OTHER Attitudes.

- 1 ☐ Families want to spare others the grief they are experiencing
- 2 ☐ Families feel that tissue donation is not necessary
- 3 ☐ Families are against patient having another surgical procedure
- 4 ☐ Families do not want to prolong the consent process
- 5 ☐ Other _____
- 6 ☐ NR/NA

8. What attitudes toward tissue donation are a spill-over from organ donation?

- 1 ☐ The patient wasn't properly helped or medically treated because s/he was on the registry
- 2 ☐ Tissue donation can be life-saving for recipients
- 3 ☐ Feelings at the time of the "pre-notification" of the request for tissues
- 4 ☐ Taking the patient's organs is a priority over saving the patient's life
- 5 ☐ The donation industry is sinister and manipulative
- 6 ☐ They will be able to meet the recipient(s)
- 7 ☐ They don't want to donate organs (carries over to tissues)
- 8 ☐ Other _____
- 8 ☐ Don't know
- 9 ☐ NR/NA

9. The spill-over from organ donation is....

- 1 ☐ Positive

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- 2 ☐ Negative
- 3 ☐ Both positive and negative
- 4 ☐ Neither positive nor negative (or no basis to tell)
- 5 ☐ Don't know
- 6 ☐ NR/NA

10. What [statements] makes you think that families have confused tissues with organs?

- 1 ☐ Families will refer to specific organs (e.g. heart, kidneys, etc.)
- 2 ☐ Families will explain to other family members that the call is about organ donation
- 3 ☐ The patient wasn't properly helped or medically treated because s/he was on the registry
- 4 ☐ Tissue donation is life-saving for recipients
- 5 ☐ Families will say they do not want to donate the patient's organs
- 6 ☐ Families will say they want to meet the recipient(s)
- 7 ☐ Families believe that the patient cannot donate tissues because s/he is already dead
- 8 ☐ Other _____
- 9 ☐ Don't know
- 10 ☐ NR/NA

11. Why do you think families confuse tissues with organs?

- 1 ☐ It's easier for family members to understand (by generalizing)
- 2 ☐ Families are more comfortable talking about organs with others
- 3 ☐ Lack of education/knowledge
- 4 ☐ It's an automatic connection they can make
- 5 ☐ TV shows/movies/media
- 6 ☐ Other _____
- 7 ☐ Don't know
- 8 ☐ NR/NA

12. Are people's attitudes toward tissue donation affected by a family member or the patient having a donor card?

- 1 ☐ Yes
- 2 ☐ No
- 3 ☐ Don't know
- 4 ☐ NR/NA

13. How often are people's attitudes toward tissue donation affected by a family member or the patient having a donor card?

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- 1 ☐ Never
- 2 ☐ Not often
- 3 ☐ Sometimes
- 4 ☐ Often
- 5 ☐ Always
- 6 ☐ Don't know
- 7 ☐ NR/NA

14. What external factors contribute to families' attitudes?

- 1 ☐ The family's overall hospital experience
- 2 ☐ The funeral home's attitudes toward tissue donation
- 3 ☐ Age
- 4 ☐ Education
- 5 ☐ Cause of death
- 6 ☐ Knowledge of patient's donor registration status
- 7 ☐ Timing of request
- 8 ☐ Stage of grief
- 9 ☐ How they cope/handle stress
- 10 ☐ Associating tissue donation with organ donation
- 11 ☐ Knowledge about tissue donation
- 12 ☐ Being registered donors themselves
- 13 ☐ Receptivity to new information/explanation
- 14 ☐ Having had a discussion about donation with patient
- 15 ☐ Who around them is influencing their decision
- 16 ☐ Need to help others
- 17 ☐ Media/TV/Movies
- 18 ☐ Other _____
- 19 ☐ Don't know
- 20 ☐ NR/NA

15. What strategies do you use to overcome misconceptions?

- 1 ☐ Explain tissue donation to families in layman's terms
- 2 ☐ Describe how reconstruction of the patient's body is done/prostheses
- 3 ☐ Describe the recovery of tissue from the patient
- 4 ☐ Explain how the patient's appearance will not be altered
- 5 ☐ Focus on the benefits of tissue donation for others
- 6 ☐ Clarify what the preclusions or rule-outs would be for donation
- 7 ☐ Provide basic education
- 8 ☐ Explain the difference between organ and tissue donation
- 9 ☐ Explain the logistics of tissue donation
- 10 ☐ Ask the family to explain what they're thinking or why
- 11 ☐ Refer to the patient being on the registry

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- 12 ☐ Give personal stories
- 13 ☐ Assure families that there will be no incisions on the face
- 14 ☐ Other _____
- 15 ☐ Don't know
- 16 ☐ NR/NA

15a. Do these strategies work?

- 1 ☐ Yes
- 2 ☐ No
- 3 ☐ It depends
- 4 ☐ Don't know
- 5 ☐ NR/NA

15b. How often do these strategies work?

- 1 ☐ Never
- 2 ☐ Not often
- 3 ☐ Sometimes
- 4 ☐ Often
- 5 ☐ Always
- 6 ☐ Don't know
- 7 ☐ NR/NA

16. What are families' positive initial reactions to the request for tissue donation?

- 1 ☐ They are excited to donate their loved one's tissues
- 2 ☐ They are familiar with the OPO and want to donate
- 3 ☐ They want to look at their loved one's license
- 4 ☐ They remember a conversation about tissue donation at the hospital/elsewhere
- 5 ☐ They are engaged in the conversation
- 6 ☐ They mention that they know someone who has donated tissue or been a recipient
- 7 ☐ They want to honor patient's giving personality
- 8 ☐ They want us to take all we can
- 9 ☐ They want us to help as many people as possible
- 10 ☐ Other _____
- 11 ☐ Don't know
- 12 ☐ NR/NA

17. What are families' negative initial reactions to the request for tissue donation?

- 1 ☐ They simply say "No"
- 2 ☐ They say the TR is a horrible person

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- 3 ☐ They think the TR is trying to sell them something
- 4 ☐ They will say why they don't think donation is a good idea
- 5 ☐ They are angry in general
- 6 ☐ They are abrupt
- 7 ☐ They are fearful of mutilation of their loved one's body
- 8 ☐ Other _____
- 9 ☐ Don't know
- 10 ☐ NR/NA

18. What are families' other initial reactions to the request for tissue donation?

- 1 ☐ They can't make this decision (general)
- 2 ☐ They can't make this decision alone
- 3 ☐ Curious about tissue donation
- 4 ☐ Surprised/caught off guard
- 5 ☐ Silence
- 6 ☐ Confusion
- 7 ☐ They will ask a question
- 8 ☐ They will try to recall a discussion with their loved one
- 9 ☐ Other _____
- 10 ☐ Don't know
- 11 ☐ NR/NA

19. Issues/statements brought up by families who are initially favorable to the request?

- 1 ☐ They are surprised by the wide range of gifts
- 2 ☐ They don't want the funeral to be delayed
- 3 ☐ They have questions about the patient's appearance
- 4 ☐ They want to know if they can still have a viewing
- 5 ☐ Will they be able to meet the recipient(s)
- 6 ☐ Logistics/timing of completing paperwork
- 7 ☐ They are overwhelmed with the length of paperwork
- 8 ☐ They are put off by the invasiveness of the med/soc
- 9 ☐ They think they have to go to the hospital to give consent
- 10 ☐ Will it cost the family any money to donate
- 11 ☐ The time it will take to recover the tissues
- 12 ☐ How soon they can see their loved one
- 13 ☐ They want tissue donation to be explained in more detail
- 14 ☐ They want their loved one to live on through donation
- 15 ☐ None, they just listen
- 16 ☐ Other _____
- 17 ☐ Don't know
- 18 ☐ NR/NA

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20. Issues/statements brought up by families who are initially unsure to the request?

- 1 ☐ They are unsure of their loved one's wishes
- 2 ☐ Appearance
- 3 ☐ Time
- 4 ☐ Unsure of ability to donate if not cremating patient
- 5 ☐ Unsure if cremation is possible with prosthetics replacing the tissues
- 6 ☐ They want the whole family's opinion about donation
- 7 ☐ Can they still donate 'organs' since patient is dead
- 8 ☐ They want to know if a funeral is still possible
- 9 ☐ Concern about loved one having another surgical procedure
- 10 ☐ They don't want patient to go through any more trauma or suffering
- 11 ☐ They just want it to be all done with
- 12 ☐ Can they still have a viewing
- 10 ☐ They question the suitability of patient's tissues to donate
- 11 ☐ They delay making a decision because they don't want to say no
- 12 ☐ They don't want patient cut on
- 10 ☐ They don't want to think about it at that time
- 11 ☐ They want their loved one to have what they came into the world with
- 12 ☐ Disbelief
- 13 ☐ They feel overwhelmed with all the tasks/duties surrounding patient's death
- 14 ☐ They want/need more information
- 15 ☐ Other _____
- 16 ☐ Don't know
- 17 ☐ NR/NA

21. Issues/statements brought up by families who are initially unfavorable to the request?

- 1 ☐ Their loved one has suffered enough
- 2 ☐ They don't want their loved one cut on
- 3 ☐ Their loved one can still feel what's going on
- 4 ☐ They are too emotional to engage in conversation
- 5 ☐ Simply "no"
- 7 ☐ Their loved one didn't sign up to be a donor
- 8 ☐ They don't want to delay the funeral arrangements
- 9 ☐ It's a terrible time to ask
- 10 ☐ They never discussed donation with loved one
- 11 ☐ It's against patient's religion
- 12 ☐ It's against family's religion
- 13 ☐ It's not right
- 14 ☐ They want to make the same decision they did with another family member
- 15 ☐ They remember the negative experience at the hospital
- 16 ☐ They remember the negative experience at the ME's office
- 17 ☐ They remember the negative experience with law enforcement

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- 18 ☐ They are against donation in general
- 19 ☐ Viewing
- 20 ☐ Time constraints
- 21 ☐ They are angry with their loved one
- 22 ☐ They are disappointed with their loved one
- 23 ☐ Other _____
- 24 ☐ Don't know
- 25 ☐ NR/NA

22. Do you see much public education on tissue donation?

- 1 ☐ Yes, a lot
- 2 ☐ Yes, some
- 3 ☐ No
- 4 ☐ Don't know
- 5 ☐ NR/NA

23. What public education on tissue donation do you see?

- 1 ☐ Community events where staff from LifeNet do presentations
- 2 ☐ Signing up on the donor registry
- 3 ☐ Driver's education programs
- 4 ☐ A poster at the DMV
- 5 ☐ A discussion at the DMV
- 6 ☐ A pamphlet at or from the DMV
- 7 ☐ In school as an SOL requirement
- 8 ☐ At a concert near LifeNet headquarters
- 9 ☐ Nothing outside of LifeNet's (or people in the industry) efforts
- 10 ☐ By word of mouth from friends or family who registered as a donor
- 11 ☐ A bumper sticker on someone's car (usually about organ donation)
- 12 ☐ None specifically on tissue donation, only organ donation
- 13 ☐ Other _____
- 14 ☐ Don't know
- 15 ☐ NR/NA

24. What do you think would be the most important message(s) to include in an educational intervention about tissue donation for the general public?

- 1 ☐ What the tissues can do
- 2 ☐ Tissue donation does not affect the appearance of your loved one
- 3 ☐ Tissue donation allows you to leave a legacy of your loved one behind
- 4 ☐ Something good that can come out of something bad
- 5 ☐ The number of individuals that can be helped by one tissue donor
- 6 ☐ Tissue donation can be life-saving/life-enhancing

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- 7 ☐ Distinguishing between organ and tissue donation
- 8 ☐ Showing how organ and tissue donation complement each other
- 9 ☐ Tissue donation improves health
- 10 ☐ It really impacts lives - Put a face with a story and a situation
- 11 ☐ How certain tissues help people walk
- 12 ☐ Tissues can give individuals the ability to hold someone
- 13 ☐ Tissues can give individuals the ability to look better
- 14 ☐ How cornea donation can help 2 people see in 2 weeks
- 15 ☐ The short-term benefits of tissue donation
- 16 ☐ Statistics on the need for tissue donors (ie.# people waiting for tissues)
- 17 ☐ Other _____
- 18 ☐ Don't know
- 19 ☐ NR/NA

25. Do you think an educational message about tissue donation should be separate from organ donation?

- 1 ☐ Yes
- 2 ☐ No
- 3 ☐ Don't know
- 4 ☐ NR/NA

26. What group(s), if any, would you target to educate about tissue donation?

- 1 ☐ Younger generation (<30) (Go to Q26a)
- 2 ☐ Middle age (30-60) (Go to Q26b)
- 3 ☐ Older generation (>60) (Go to Q26c)
- 4 ☐ Hispanic community (Go to Q26d)
- 5 ☐ African American community (Go to Q26e)
- 6 ☐ Spouses (Go to Q26f)
- 7 ☐ Parents of young children (Go to Q26g)
- 8 ☐ Children (Go to Q26h)
- 9 ☐ Everyone (Go to Q26i)
- 10 ☐ Other (Go to Q26j) _____
- 11 ☐ Don't know
- 12 ☐ NR/NA

26a. Why would you target the **younger generation**?

- 1 ☐ They don't know enough about it
- 2 ☐ They are the healthiest donors
- 3 ☐ They become the decision-makers for tissue donation
- 4 ☐ They are starting to formulate their own attitudes towards donation
- 5 ☐ They are best suited to have discussions with their family members

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- 6 ☐ Other _____
- 7 ☐ Don't know
- 8 ☐ NR/NA

26b. Why would you target the **middle age**?

- 1 ☐ They don't know enough about it
- 2 ☐ They don't realize what they checked off on their license
- 3 ☐ They experience the most despair upon death of a loved one
- 4 ☐ Their attitudes are more strongly engrained
- 5 ☐ Other _____
- 6 ☐ Don't know
- 7 ☐ NR/NA

26c. Why would you target the **older generation**?

- 1 ☐ They don't know enough about it
- 2 ☐ They have misconceptions about suitability of tissues
- 4 ☐ They don't understand what tissue donation can do for others
- 5 ☐ They make up a large percentage of actual tissue donors
- 6 ☐ Other _____
- 7 ☐ Don't know
- 8 ☐ NR/NA

26d. Why would you target the **Hispanic community**?

- 1 ☐ They don't know enough about it
- 2 ☐ They are neglected in society due to language barrier
- 3 ☐ They have no exposure to tissue donation
- 4 ☐ Other _____
- 5 ☐ Don't know
- 6 ☐ NR/NA

26e. Why would you target the **African American community**?

- 1 ☐ They don't know enough about it
- 2 ☐ They have no exposure to tissue donation
- 3 ☐ There is much confusion between organ and tissue donation
- 4 ☐ They don't trust that organs/tissues will be allocated fairly
- 5 ☐ They believe tissues will be taken while loved one is still alive
- 6 ☐ They believe not everything will be done to save loved one if donor card is marked
- 7 ☐ There is a lack of trust in the medical field/research in general
- 8 ☐ Other _____

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- 9 ☐ Don't know
- 10 ☐ NR/NA

26f. Why would you target **spouses**?

- 1 ☐ They are most emotional at time of a loved one's death
- 2 ☐ They comprise the majority of legal next of kin
- 3 ☐ They can inform their significant other of their wishes
- 4 ☐ They are most likely to follow-through with their significant other's wishes
- 5 ☐ Other _____
- 6 ☐ Don't know
- 7 ☐ NR/NA

26g. Why would you target **parents (of young children)**?

- 1 ☐ They are most likely to donate
- 2 ☐ They need to make sense of death
- 3 ☐ They want their loved one to live on
- 4 ☐ Heart valves, which typically come from young children, are in demand
- 5 ☐ Other _____
- 6 ☐ Don't know
- 7 ☐ NR/NA

26h. Why would you target **children**?

- 1 ☐ So they can educate their parents
- 2 ☐ They are most receptive to new information
- 3 ☐ Other _____
- 4 ☐ Don't know
- 5 ☐ NR/NA

26i. Why would you target **everyone**?

- 1 ☐ Everyone can benefit
- 2 ☐ Not enough information out there in general
- 3 ☐ Other _____
- 4 ☐ Don't know
- 5 ☐ NR/NA

26j. Why would you target _____(specify_____)?

- 1 ☐ Other _____
- 2 ☐ Don't know
- 3 ☐ NR/NA

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27. Through which medium do you think tissue donation should be publicized?

- 1 ☐ Billboards
- 2 ☐ TV commercials
- 3 ☐ On TV shows
- 4 ☐ Brochures
- 5 ☐ Internet
- 6 ☐ A book to read while waiting at the DMV
- 7 ☐ Other _____
- 8 ☐ Don't know
- 9 ☐ NR/NA

28. Do you think that educating the public about tissue donation would help to increase consent rates?

- 1 ☐ Yes
- 2 ☐ No
- 3 ☐ Don't know
- 4 ☐ NR/NA

28a. Probe to Q28, Why?

- 1 ☐ It will make the decision much easier later on
- 2 ☐ Families will be able to have a more informed consent
- 3 ☐ Families will be better educated on the subject
- 4 ☐ Families will be more comfortable with the topic through previous exposure
- 5 ☐ Families will have a greater willingness to donate
- 6 ☐ Families can distinguish between organs and tissues
- 7 ☐ Families will understand other ways to help others aside from organ donation
- 8 ☐ Families will associate tissue donation with saving lives
- 9 ☐ Families will have less fears about tissue donation
- 10 ☐ It will prepare families for a future request over a telephone call
- 11 ☐ It will encourage more discussions
- 12 ☐ Other _____
- 13 ☐ Don't know
- 14 ☐ NR/NA

Appendix C

CODING MANUAL FOR TISSUE REQUESTERS' PERSPECTIVES

Understanding the Public's Attitudes Toward Tissue Donation: A Multi-Method
Approach

PRIMARY DATA SOURCE: INTERVIEWS WITH TISSUE REQUESTERS AT LIFENET
HEALTH IN VIRGINIA BEACH, VA

Lindsey Kurland
Advisor: Laura A. Siminoff, Ph.D.
Virginia Commonwealth University

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GENERAL INSTRUCTIONS

1. Only begin coding cases you are assigned after you have read through this coding manual thoroughly.
2. The codes in the instrument included here are in the same order and in **bold**. Descriptions for these codes are written beneath the bolded codes and are in *italics*.
3. Please pay close attention to the statements in the coding manual that are underlined, which will give specific instructions for whether the question requires a single code or multiple codes.
4. If you have a code that does not clearly fit into one of the already established codes on the instrument, please use the "other" space provided to write in the appropriate code.
5. Cross-coding is allowed. Cross-coding occurs when the tissue requester (TR) says something that can be coded in another question.

CODING INSTRUCTIONS

1. How much knowledge do families have about tissue donation?

This question pertains to Question 1 asked in the Tissue Requester Interview Guide. This question has a 5-point Likert scale for how much knowledge TRs believe families have, from no knowledge to a lot of knowledge. Choose only one answer below for this question. TRs might say more than one answer, for example, "Families have some knowledge", and then later say, "Families don't really know anything about tissue donation." In this case, choose the code that the TR describes more about. If there is an equal amount of information the TR provides for both codes, choose the code for what the TR says second in the interview.

- 1. Families have no knowledge about tissue donation**

Use this code when TR says that families have no knowledge about tissue donation.

- 2. Families have very little knowledge about tissue donation**

Use this code when TR says that families don't know very much about tissue donation or have very little knowledge. Families may express surprise that tissue donation exists, or have little ability to distinguish between tissue and organ donation.

- 3. Families have some knowledge about tissue donation**

Use this code when TR says families have some or an average amount of knowledge about tissue donation. TR may say 50% families know about donation, that knowledge levels vary, that the knowledge level is 50/50, etc.

- 4. Families have more than some knowledge about tissue donation**

Use this code when TR says families have above average knowledge about tissue donation. For example, TR may say that families are familiar with tissue donation.

- 5. Families have a lot of knowledge about tissue donation**

Use this code when TR says families have a lot of knowledge about tissue donation. For example, TR may say that most families are highly knowledgeable because at

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least one member of the family works in healthcare or because at least one member of the family previously has been through a donation request following the passing of a loved one.

6. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

7. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

2. What knowledge about tissue donation do families have?

This question pertains to Question 1 in the Tissue Requester Interview Guide. Multiple codes can be chosen for this question.

1. Families think that tissue donation is like organ donation

Use this code when TR says that families confuse tissue donation with organ donation, says they are similar or refers to organ donation in general.

2. Families are familiar with heart valves and eyes

Use this code when TR says that families are specifically familiar with tissues like heart valves and eyes. These tissues seem to be more memorable to families according to LifeNet Health TRs.

3. Families' knowledge comes from knowing someone that has been a recipient of tissue donation

Use this code when TR says that families' knowledge about tissue donation comes from personal experience of knowing someone, whether a family member, friend, or other person, who has been a recipient of tissue donation. For example, TR might say that families know someone who has had a procedure such as knee replacement, hip replacement, or dental implants.

4. Families have no knowledge about tissue donation

Use this code when TR says that families do not know anything about tissue donation or have very little understanding of it.

5. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

6. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

3. What knowledge do families lack?

This question pertains to Question 1 in the Tissue Requester Interview Guide. Multiple codes can be selected for this question.

1. Families are not aware that tissue donation is an option

Use this code when TR says that families have no awareness of tissue donation or that it exists as an opportunity, or if families persistently confuse the conversation to

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be about organ donation. Referencing organ donation, families may say, "We were not aware that tissue and eye donation goes along with that."

2. Families don't understand the purpose/function of tissues

Use this code when TR says that families have trouble understanding what the tissues are for, their function or purpose, or general uncertainty as to how the tissues will be used.

3. Families don't know the types of tissues possible to donate

Use this code when TR says that families do not know what types of tissues can be donated. This code has to do with the various types such as skin, bone, muscle, and corneas.

4. Families have trouble understanding the application of bone/skin grafts

Use this code when TR says that families specifically don't understand how grafts such as bone and skin are used.

5. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

6. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

Questions 4.-7. are the same as Questions 1.-4. on the Audiofile Coding Instrument; however, here they refer to "families" in general since these codes refer to the TRs' perspectives. Multiple codes can be selected per question. Please note that for questions 4-7, codes may come up in other parts of the interview that should still be coded here.

29. What are some of the affective attitudes families have?

The question in the TR Interview Guide is asked as, "Do families have attitudes that are based in an emotional response to the idea of tissue donation?"(Q2 on Tissue Requester Interview Guide).

C. Positive: Positive affective codes reflect the families' affective attitudes that are in favor of tissue donation in some way, from the tissue requester's perspective.

1C. Families are excited

Use this code when TR says that families are very happy about donating patient's tissues. TR might say, "He was very passionate about donation". TR may say that families are enthusiastically cooperative, very talkative, energetic, or on the other hand, brief and anxious to wrap up the consent process so they can donate ASAP.

2C. Families feel good

This code should be used when TR makes a statement referring to how families feel positively towards donating their loved one's tissues. TRs may say that families feel at peace with their decision, that they are honoring their loved one, that through their loss, they can help someone else, or are satisfied with their decision about donation. Also, families might not articulate specifically that they feel good, but may illustrate it by being noticeably positively

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impacted by the decision to donate; for example, a family that is initially against, changes its opinion after TR explains how donation can save lives, and is then relieved to do something positive.

3C. Families feel grateful

This code should be used when TR says that families express appreciation for the opportunity to donate, whether or not the families decide to donate. Families may be grateful that the donation will help them cope, that it will help fulfill patient's wishes, or that it will help others.

4C. Other: _____

Use the "Other" code when you hear something the TR says that is a positive affective attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

5C. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

6C. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

D. Negative: Negative affective codes reflect the families' affective attitudes that are *NOT* in favor of tissue donation in some way, from the tissue requester's perspective.

1D. Families feel guilty

Use this code if TR says that families do not want to upset the family or feels upset or guilty in general about decision. Also use this code if families have a difficult time making the decision on their own or want the advice/input of other family members and/or friends.

2D. Families experience the "ick factor"

The "ick" factor is a negative emotional reaction of disgust to the idea of tissue donation, in this case. Use this code if TR says that families respond to the request of tissue donation with disgust, for example with a statement such as, "Ew!", "That's gross!", or says that anything regarding tissue donation makes them feel squeamish or uncomfortable.

3D. Families feel that tissue donation is barbaric

Use this code when TR says that families use the term "barbaric", "mutilated", or use a similar description of tissue donation. TR might say that families think that tissue donation is eerie, inhuman, or heartless for which you would use this code.

4D. Families feel that tissue donation is offensive

The TR will say that families are offended by the request for tissue donation. Use this code if the TR says families are offended by not only the call/request, but by any part or process of tissue donation or by tissue donation itself.

5D. Families feel that request too difficult to understand at raw moment in life

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This code should be used when TR says that families feel too tired or overwhelmed with the request for tissues and have trouble thinking about it at the time. TR may say, "some families handle death better than others."

6D. Families do not want patient's body to be touched

This code should be used when the TR says families do not want the patient's body touched by anyone on the donation team.

7D. Families do not want patient's body to be cut on

Use this code if TR says families refers to mutilation, disfigurement, the patient being cut on or cut into.

8D. Family has been through enough already

Use this code when the TR says that families feel they have "been through enough" with patient's death or medical illness.

9D. Families feel that the patient has been through enough already

Use this code if TR states that families feel the patient has suffered through enough either through death or with medical illness.

10D. Families want to remember patient the way s/he was

Use this code when TR states that families say, "I don't want him to be any different than how I remember him" or "I want to remember him the way he was."

11D. Families feel the details of tissue donation not important

Use this code when TR says families do not need to hear any further because they already know about tissue donation or is not interested in knowing. Frequently, the family has made up their mind, which contributes to lack of interest in details.

12D. Tissue donation conjures negative imagery

Use this code when TR says that families talk about tissue donation being too graphic or they are "imagining" something horrible, such as amputation, happening to the patient's body. This code should be used when TR says families describe a negative image that come to mind when they think about tissue donation.

13D. Families feel that donating tissues is going too far

Use this code when TR says families feel that donating the patient's tissues is too much to donate. A situation might be when families donated the patient's organs and they feel that donating the tissues is going too far.

14D. Other: _____

Use the "Other" code when you hear something that is a negative affective attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

15D. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

16D. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

30. What are some of the behavioral attitudes families have?

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In the TR Interview Guide, Q2, the question is asked as, "Do you believe that a patient having a donor card affects families' attitudes?"

- A. Positive:** Positive behavioral attitude codes are behaviors that are *in the direction* of donating tissues.
- 1A. Families are registered donors**
Use this code if TR says that families somehow indicate that they are signed up on the donor registry and intends to one day donate.
 - 2A. Families supports patient's wishes**
This code should be used when the TR says that families say they have always supported patient's endeavors, wishes, etc. and want to follow the patient's wishes here as well. This code should also be used if the TR says "yes" to the question about the patient having a donor card impacting the families' attitudes.
 - 3A. Families had a discussion about donation with patient**
Use this code if TR says that families talked to patient about tissue donation or patient's donation wishes. This code can also be used if TR says that patient told families what s/he wanted to do regarding donation.
 - 4A. Families told patient tissue donation was a good thing to do**
Use this code if TR says that families say they told patient at some point that they thought donation was a good thing to do. For example, "Before my daughter got her license she asked me about donating her organs and tissues and I told her I thought it was a worthy cause."
 - 5A. Families have discussed donation with family**
This code should be used when TR says that families say they have had conversations about donation with family members (ie. parents, siblings, cousins, grandparents, children, etc)
 - 6A. Families have discussed donation with friends**
Use this code when TR says that families say they have had conversations about donation with friends
 - 7A. Families have discussed donation with others**
Use this code when TR says that families say they have had conversations about donations with others (ie. co-workers, members at his/her church, funeral home personnel, acquaintances, etc.). This code may also be used if TR says that families do not specify who they spoke with, but just says that they've spoken to people in general.
 - 8A. Families have donated before**
This code should be used when the TR says that families mention any sort of previous experience donating, whether it's tissues or something else like blood, bone marrow, etc. An example might be that family says, "I've donated blood before."
 - 9A. Families are involved with donation in some way (Specify how_____)**
Use this code when TR says that families are involved with donation in some form. For example, families might be volunteers at organ donation marathons

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every year, may be involved with the hospital to promote donation, or may be a philanthropist for organ/tissue donation campaigns. Also use this code if TR says that family says they have another family member or relative who was a recipient of donation.

10A. Other: _____

Use the "Other" code when you hear something that is a positive behavioral attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

11A. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

12A. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

B. Negative: Negative behavioral attitude codes are behaviors that are in the direction of *refusing* tissue donation.

1B. Families told patient tissue donation was NOT a good thing to do

Use this code when TR says that family talked to patient and told patient they didn't think tissue donation was a worthwhile cause. For example, "When my son got his license and told me he registered to be a donor, I told him I didn't like the idea."

2B. Families are NOT registered donors

Use this code when TR says that families specifically say they are not donors or do not intend to be.

3B. Families do NOT support patient's wishes

Use this code when TR says that families say that they do not support patient's wishes. For example, after the TR may say that patient is on the registry, families might say, "It doesn't matter. We're just not comfortable with it," or "I know he was registered, but I don't want him cut on."

4B. Families have discussed donation with family

This code should be used when families say that they have had conversations about NOT wanting to donate with other family members (ie. parents, siblings, cousins, grandparents, children, etc)

5B. Families have discussed donation with friends

Use this code when families say that they have had conversations with friends about NOT wanting to donate or being against donation

6B. Families have discussed donation with others

Use this code when TR says that families have had conversations with others (ie. co-workers, members at his/her church, funeral home personnel, acquaintances, etc.) about NOT wanting to donate or being against donation. This code may also be used if TR says that families do not specify who they spoke with, but just say that they've spoken to people in general.

7B. Other: _____

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Use the "Other" code when you hear something that is a negative behavioral attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

8B. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

9B. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

31. What are some of the cognitive attitudes families have? *This question refers to Q2 in the TR Interview Guide which asks, "What information is based on facts that may be correct or incorrect?" and Q3 on the TR Interview Guide "What misconceptions are most common?"*

A. Positive: Positive cognitive attitude codes are cognitive-based beliefs, whether correct or incorrect, that *support* donating tissues.

1A. Families believe it's the right thing to do

Use this code when TR says that families express some sort of moral imperative to donate patient's tissues. Families might say, "We think it's the right thing to do".

2A. Families believe it's better the tissue is used than unused

Use this code if TR says families refer to tissues going to waste if not used or say something like, "why not if it can do some good." Also use this code when TR says that families say, "You can use whatever you can".

3A. Families believe that patient is just a body, not a person

This code should be used when TR says families state that the patient is no longer a person, s/he is just a shell or body. Families acknowledge that the patient is no longer alive and may say this to justify why they are ok with donating patient's tissues.

4A. Families believe tissue donation saves lives

TR says that families may be confusing tissues with organs in terms of their life-saving capacity. Nonetheless, use this code if TR says that families say that tissue donation saves people's lives.

5A. Families believe tissue donation helps people

Use this code if TR says families say that tissues help others. For example, they may say, "if it helps others....". This code may be used if families discuss how tissues may improve the health of others or do "some good".

6A. Other: _____

Use the "Other" code when you hear something that is a positive cognitive attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

7A. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

8A. NR/NA

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Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

- B. Negative:** Negative cognitive attitude codes are cognitive-based beliefs that support *NOT* wanting to donate tissues.

1B. Families believe donation will alter patient's appearance

Use this code when TR says families think tissue donation will affect the patient's appearance or how the patient looks.

2B. Families believe there will be nothing left of patient

This code should be used when TR says families say "there will be nothing left of patient to bury" or "they'll take so much that there won't be anything left of him." Basically, families are concerned that after the tissues are procured there will not be anything left over for any purpose, whether it be for burial, to touch, etc.

3B. Families believe patient is still alive in some way

This code refers to when TR states that families make statements about the patient in the present tense or says something to show that they still think of patient as being alive. Families might say, "We don't want him to suffer any more" eluding to the fact that patient is still alive and can feel the surgery being done to remove the tissues.

4B. Families believe tissue donation will delay the funeral

Use this code when TR says families do not want the funeral to be delayed or they think tissue donation will delay the funeral.

5B. Families believe tissue donation will affect the viewing

Use this code when TR states that families do not believe they can donate because donation will impact the viewing. For example, families might say, "We're not sure [about tissue donation] because we want her to have a viewing" indicating that this false belief is affecting the family's decision to donate. This code can also be used when family says something specific like, "you can't take his hands because you'll be able to tell at the funeral."

6B. Families believe patient's body will not be treated with respect

Use this code when TR says families express concern about the staff not acting in a professional manner with patient's body, that they do not know what will happen behind closed doors once they agree to donation, or questions how the patient's body is handled.

7B. Families believe that patient's tissues are not suitable for donation

This code should be used when families make statement about patient's suitability to donate or the viability of his/her tissues. Families will usually explain why they believe the patient is not eligible for donation or why the TR would not be interested in taking the patient's tissues. Families might say "his tissues won't do you any good" or "no one will be able to use them" or "I don't think you can use his tissues." Families might explain that the patient had broken bones, s/he used glasses or that his/her eyes cannot be donated because they had cataract surgery or glaucoma, to name a few examples.

8B. Families believe that tissue donation will cost them money

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Use this code if families indicate that they think donation will cost them money. Families may say, "we can't afford to do this" or "the funeral home will charge more for this". Generally this code should be used for a family's misconception about the altruistic nature of tissue donation, that tissue donation is not a gift, that there is a financial commitment attached to donation.

9B. Families believe that tissue donation is only possible with cremation

Use this code if families specifically mention cremation. Families may couch this thought with the fact that they are having a funeral or want to have a viewing. Families might say "well we're not having him cremated", something to indicate that they think donation is contingent upon having patient cremated.

10B. Families think they have to go to the hospital to donate patient's tissues

This code should be used when families discuss going to hospital to fill out paperwork in order to donate. Families might talk about their schedule and when they might be able to meet up with the TR to sign the paperwork before they are aware that consent takes place over the telephone.

11B. Families believe that the patient will not be able to be buried

This code is specifically for when families have a concern about the burial. Families believe that it will be difficult to have a burial or that it will not be able to be done because of the way tissue donation is.

12B. Families think that not enough medical attention will be provided to patient

Use this code when families make a statement referring to the false belief that not everything will be done to save patient or the patient will not be saved if in an accident and is a donor.

13B. Families think patient is too sick to donate/has too many medical Conditions

This code is similar to code 7B above regarding suitability and may be coded in addition to 7B, but this code is more specific. Use this code when families talk specifically about the patient being too sick, having been through too much, or having had too many medical conditions in the context of suitability of patient's tissues. Families may mention that patient had cancer, was on chemotherapy, or had multiple heart surgeries and was diabetic.

14B. Families think that rich people get organs/tissues faster

Use this code if families say anything about celebrities or wealthy people, people who have the financial means are more likely to receive and reap the benefits of the donated tissues. Families might mention something they saw on TV, i.e. Dick Cheney receiving a heart shortly after being placed on waiting list and thinking this happened because he's a famous politician.

15B. Families believe that patient's body parts will be taken

Use this code if families mention body parts being taken from patient. Families might use the terms: limbs, extremities, arms, amputate, and legs.

16B. Families believe tissue donation does NOT save lives

Use this code if families feel that tissue donation only enhances lives or improves the quality of lives or specifically says that it does not save lives. Families are concerned that donation will not be used in a life-saving capacity. Families might compare to organs, saying that it doesn't help people the way organs do.

17B. Families believe tissue donation industry is all profit-driven

This code should be used when families state that companies, pharmaceuticals or others will profit off of donated tissues and this makes family uneasy. Families might make a more general comment about the tissue donation industry. Families need to make a statement beyond just that want the tissues to be donated to non-profit companies or that they do not want it to go to for-profit companies. Families need to express more about what they think.

18B. Families believe tissue donation industry is sinister and manipulative

This code should be used when families express distrust in donating tissue to those that receive the tissues. Families may talk about people stealing body parts and selling them for profit, or that companies are sneaky or not looking out for the best interest of the donors, or that preferential treatment is given to some unjustly.

19B. Families believe tissue donation is not possible because patient is dead

This code refers to when families say "but they're dead" or "I didn't know he could donate after he's already passed" demonstrating confusion about when tissue donation takes place.

20B. Families believe tissues will be wasted (i.e. 'thrown away')

This code should be used in two scenarios. One scenario is when the family thinks that the tissues will be thrown away if not donated – they might say "they'll be thrown away anyway, so why not?". The second scenario is when the family thinks that during procurement of tissues, some tissues will be kept and others will be thrown away, that not all of it will be donated and that concerns family.

21B. Families think patient is too old to be on registry/donate

Use this code when family mentions that the age of the patient would prohibit him/her from donating tissues. Family may also say that their loved one was too old to be on the registry. Use this code whenever family refers to the patient being too old to donate.

22B. Families believe they will not be able to see patient again

Use this code if families express concern about not being able to see the patient after donation takes place, whether because the body will be sent directly to the funeral home, to be cremated, or because the procurement team will keep families from seeing patient again. This code can also be used if families do not think they will be able to see the patient again due to his/her appearance after the procurement of tissues (i.e. skin donation will make it difficult for families to see patient again).

23B. Families think the patient will not feel the same

Use this code when families state that the patient will literally not feel the same as far as when they touch their loved one or holding his/her hand it

won't be the same. Families may state that other parts of the patient's body will not feel the same.

24B. Families think the patient will not look the same

This code should be used when families are specifically concerned or state that their loved one will not look the same, will look different than before or anything that has to do with the patient's appearance being altered or different.

25B. Families believe the patient wanted to go out of the world the way he came into it

Use this code when families talk about patient's wishes as far as his/her body is concerned (being whole after death versus donating parts of body). Families may state, "s/he wanted to go out of the world the way s/he came into it". Families might say this generally or in the religious sense.

26B. Families want the patient to go out of the world the way he came into it

Use this code when families talk about how they want the patient to leave the world the way s/he came into it (being whole after death versus donating parts of body). Families may state, "We think Sam should go out of the world the way s/he came into it". Families might say this generally or in the religious sense.

27B. Families think it's against patient's religion

Use this code when families say that tissue donation is against patient's religion. Families may explain that patient did not believe in this sort of thing, or "s/he was a Christian" "s/he was Jewish" and that "this is not something s/he would agree with."

28B. Families think it's against NOK's religion

This code should be used when families do not say that it was against patient's religion but states directly or indirectly that they do not agree with donation due to religious beliefs. For example, families might say, "The bible says this sort of thing isn't acceptable if you want to get into heaven."

29B. Families believe the eyes are the windows to the soul

This code specifically refers to the donation of the patient's eyes or corneas. Families will state a spiritual belief about the eyes such as that they are the windows to the soul.

30B. Families believe the patient needs all his/her parts to get into heaven

This code is similar but slightly different than code 28B above "it's against families' religion". This code should be used only when families state that the patient needs all his/her parts to go to heaven. Families do not need to make a statement about it being against families' or patient's religion in order for this code to be used. Families may state that they do not know if the patient will need his/her organs or tissues in the afterlife.

31B. Families think the patient's tissues will not do any good

Use this code when families express their concern about the patient's tissues not doing any good. They might say, "I really don't think his tissues will help anybody". This code may be used in tandem with code 7B (suitability).

32B. Other: _____

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Use the "Other" code when you hear something that is a negative cognitive attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

33B. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

34B. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

7. Families' OTHER Attitudes

These attitudes are categorized as "other" as they do not cleanly fit into any of the three cognitive components, affective, behavioral, nor cognitive. This refers to Q2 of the TR Interview Guide, which asks about attitudes towards tissue donation outside of the cognitive components.

1. Families want to spare others the grief they are experiencing

Use this code when families state that they want to help someone else so that they don't have to go through what they are going through. Families might say, "I don't wish this on anyone."

2. Families feel that tissue donation is not necessary

Use this code when families say something to reflect that they feel that tissue donation is not an important endeavor, that it's a waste of time, or that it's not less important than organ donation. An example might be, "We already donated Jane's organs. I don't feel the need to donate more."

3. Families are against patient having another surgical procedure

Use this code if the families say, "Another surgery is too much" or "I don't want him to go through another surgery." This code may come up after the TR says that the procurement process is similar to that of a surgery.

4. Families do not want to prolong the consent process

Use this code if families express urgency to finish the process or get the body to the funeral home. Use this code also if families say they just want to get this over with so they can move on.

5. Other: _____

Use the "Other" code when you hear something that is a negative cognitive attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

6. None

Choose this code when none of the above codes apply and there are no negative cognitive attitudes present.

8. What attitudes toward tissue donation are a spill-over from organ donation?

Here, spill-over refers to attitudes toward organ donation which are carried over to those toward tissue donation. Spill-over may be due to confusion, strong association, misconception, or the like. This refers to the Probe in Q2 of the TR Interview guide where the question "What attitudes do you think are a spill-over from organ donation?"

1. The patient wasn't properly helped or medically treated because s/he was on the registry

Use this code when TR states this as a spill-over attitude. This code refers to patients not being treated as they should or receiving enough medical attention because they are listed as a donor on the registry. Families may think that having one's name on the registry biases medical professionals in treating patients fairly.

2. Tissue donation can be life-saving for recipients

Use this code when TR states this as a spill-over attitude. This code is a positive spill-over attitude that often comes from organ donation: that it is life-saving for recipients.

3. Feelings at the time of the "pre-notification" of the request for tissues

This code refers to when families are usually approached at the hospital for organ donation, prior to being approached for tissue donation. During this time, families are sometimes notified, or "pre-notified", that they will be receiving a telephone call or will be contacted soon about tissue donation. When families are in an emotional state after their loved ones' passed away, they may rely on their feelings either about organ donation at the time, which may be positive or negative, to determine how they feel about tissue donation.

4. Taking the patient's organs is a priority over saving the patient's life

This code refers to when families do not want to be registered donors or have their drivers' license say "organ donor" because they are afraid or under the misconception that medical professionals will be more interested in taking his/her organs than saving his/her life.

5. The donation industry is sinister and manipulative

Use this code when TR states that families feel that the tissue donation industry is sinister, manipulative or negative in some way. Families may refer to companies making a profit or treating the rich before treating the poor. Both of these examples may be factual for the tissue donation industry, but the point here is that families are influenced by or reinforced by their negative beliefs regarding the organ donation industry.

6. They will be able to meet the recipient(s)

Use this code when TR states that families say they want to meet the individuals that the patient's tissues go to. Because there are so many recipients of tissue from just one donor, it is very difficult for families to meet the recipients. This is unlike organ donation where one donor may donate to maybe one or two individuals and can meet the recipient. For this code, families falsely believe that they may take part in the process in a similar manner to organ donation.

7. They don't want to donate organs (carries over to tissues)

Use this code when TR states that families are not willing to donate their loved one's tissues for the same reasons they are not willing to donate their organs. Often families will give a blanket "no" to all forms of donation regardless of the different characteristics of each donation.

8. Other: _____

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Use the "Other" code when you hear something that is a spill-over attitude from organ donation and does not fit into the above codes. Please summarize what code you think the statement should be.

9. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

10. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

9. The spill-over from organ donation is....

This question is directly related to Q8 above, and is specifically asking the valence of the spill-over attitude.

1. Positive

Use this code when TR states that the spill-over attitude(s) from organ donation are positive or impact attitudes toward tissue donation in a positive way. This code may also be selected if implied by the code(s) selected in Q8. For example, "Tissue donation saves lives" would be coded as a positive spill-over attitude.

2. Negative

Use this code when TR states that the spill-over attitude(s) from organ donation are negative or impact attitudes toward tissue donation in a negative way. This code may also be selected if implied by the code(s) selected in Q8. For example, "The tissue donation industry is sinister and manipulative" would be coded as a negative spill-over attitude.

3. Both positive and negative

Use this code when TR states that the spill-over attitude(s) from organ donation are both positive and negative or impact attitudes toward tissue donation in both positive and negative ways. This code may also be selected if implied by the code(s) selected in Q8. For example, "Feelings at the time of pre-notification" would be coded as both positive and negative spill-over attitudes because these attitudes may be both positive and negative, either at the same time or independently.

4. Neither positive nor negative (or no basis to tell)

Use this code when TR states that the spill-over attitude(s) from organ donation are neither positive nor negative or impact attitudes toward tissue donation in neither positive nor negative ways. This code may also be selected if implied by the code(s) selected in Q8. For example, this code might be selected for a code in the "other" code for Q8 that can neither be determined as positive or negative, but is simply an attitude toward tissue donation that is carried over from organ donation.

5. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

6. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

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10. What [statements] makes you think that families have confused tissues with organs?

This refers to Q3 of the TR Interview Guide, which focuses on misconceptions of tissue donation.

1. Families will refer to specific organs (e.g. heart, kidneys, etc.)

Use this code when TR states that families say "...so he can donate his heart [for other organ]", which clearly demonstrates that they are confused.

2. Families will explain to other family members that the call is about organ donation

Use this code when TR states that they hear families telling other families while on the phone that the call is about organ donation; families use the word organ instead of tissue when explaining tissue donation to others, sometimes to make it easier to understand, but also sometimes because they are confused about tissue donation.

3. The patient wasn't properly helped or medically treated because s/he was on the registry

Use this code when TR specifically states that families believe the patient will not be treated well medically because s/he is on the registry. This code reflects what the TR thinks indicates that families say that shows confusion between organs and tissues. This attitude clearly stems from an attitude toward organ donation and shows confusion between organs and tissues as the patient not being medically treated is not relevant once the patient is already dead, which is the case with a patient being eligible for tissue donation.

4. Tissue donation is life-saving for recipients

Use this code when TR says that families say that tissue donation saves lives. While this may be true for some tissue donations this code reflects what the TR believes is an indicator of confusion among families.

5. Families will say they do not want to donate the patient's organs

Use this code when TR states that families specifically say that they do not want to donate the patient's organs rather than tissues. Families may say this during requests because they are under the impression that the organs are being asked for instead of tissues or that this is just an extension of the previous approach for organs and that tissues are no different than organs.

6. Families will say they want to meet the recipient(s)

Use this code when TR states that families say they want to meet the recipient(s), indicating that they believe the process of tissue donation is similar to or the same as organ donation. With organ donation, donor families are allowed to meet the recipients of the patient's organs. With tissue donation, this is not possible as there may be close to 100 recipients of the patients' tissues and there is no system in place for these connections to be made.

7. Families believe that the patient cannot donate tissues because s/he is already dead

Use this code when TR states that families say that the patient cannot donate tissues because s/he died, and it's too late. This attitude conveys that families are thinking about the process of organ donation, whereby, a patient can only donate under certain circumstances (i.e. the patient is still on life supports).

8. Other: _____

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Use the "Other" code when you hear something that is an attitude that displays confusion between organ and tissue donation. Please summarize what code you think the statement should be.

9. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

10. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

11. Why do you think families confuse tissues with organs? *This question is related to Q10 above as well as Q6 of the TR Interview Guide which questions the public education surrounding tissue donation.*

1. It's easier for family members to understand (by generalizing)

Use this code when TR believes that families confuse tissues with organs because it's easier to generalize tissues as organs than to think about tissues as a separate entity.

2. Families are more comfortable talking about organs with others

Use this code when TR believes families confuse tissues with organs because it makes it easier to talk about with others (i.e. family and friends). This may be due to more people knowing about organs and because organs may be easier to conceptualize.

3. Lack of education/knowledge

Use this code when TR believes that families confuse tissues with organs because they do not possess education or knowledge on the topic.

4. It's an automatic connection they can make

Use this code when TR believes that families confuse tissues with organs because "it's an automatic connection they can make". In other words, use this code when there is any mention of families drawing similarities between organs and tissues or somehow associating the two upon first discussion on the topic. TR may say, "they don't have the separation between the two."

5. TV shows/movies/media

Use this code when TR believes that families confuse tissues with organs because of influence from TV shows, the movies, or media. These three sources may advertise distorted or false information about tissues, perhaps indicating that the two are one and the same, rather than different entities, and contribute to families' confusion about tissues.

6. Other: _____

Use the "Other" code when you hear the TR give a reason or explanation as to why families confuse tissues with organs that is not captured in one of the codes above. Please summarize what code you think the statement should be.

7. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

8. NR/NA

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Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

12. Are people's attitudes toward tissue donation affected by a family member or the patient having a donor card?

This refers to question 2 in the Tissue Requester Interview Guide which explicitly asks "Do you think people's attitudes toward tissue donation are affected by a family member or the patient having a donor card?"

1. Yes

Use this code when the TR answers "yes", "most of the time", "sometimes", or any response indicating that people's attitudes are affected by a family member or the patient having a donor card.

2. No

Use this code when the TR says "no" or anything that indicates that people's attitudes are NOT affected by a family member or the patient having a donor card.

3. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

4. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

13. How often are people's attitudes toward tissue donation affected by a family member or the patient having a donor card?

This question may not have been directly asked of the TR and it was also not explicitly stated in the Interview Guide. However, the answer to this question can be discerned from the TR's response to question 2.

1. Never

Use this code when TR responds "No" to question 12.

2. Not often

Use this code when TR says "Yes" to question 12 but then explains that the donor card does "not often" affect people's attitudes. Other terms or phrases that would merit this code are "rarely", "very few families", "not a lot", "occasionally", or "less than 50%".

3. Sometimes

Use this code when TR says "50 percent of the time", "sometimes", or anything indicating half of the time.

4. Often

Use this code when TR says "more than 50% of the time", "often", "most of the time", "98%", "99%", "2/10 will say no", or "usually".

5. Always

Use this code when TR says "always" or something to indicate that the donor card affects people's attitudes all the time.

6. Don't know

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Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

7. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

14. What external factors contribute to families' attitudes?

This question is not specifically asked in the interview; however, the codes used for this question may be addressed in previous or later questions. External factors refer to factors outside of a person's affective, behavioral and cognitive attitudinal components, perhaps from the environment or outside experiences that affect attitudes. Some of these factors may be considered covariates. This question is related to Q7 above, which relates to Q2 of the TR Interview Guide.

1. The family's overall hospital experience

Use this code when TR says that families' hospital experience affects their attitudes. Usually a negative experience is more impactful.

2. The funeral home's attitudes toward tissue donation

Use this code when TR says that families' attitudes are affected by the Funeral Director's or funeral home's attitudes toward tissue donation. A common example might be that the Funeral Director tells families that tissue donation disfigures the patient's body or tells families that donation makes their job more challenging, thus affecting their attitudes.

3. Age

An example of when this code may be used is when the TR says "I think it's something about the younger generation", something to indicate that age influences families' attitudes toward tissue donation.

4. Education

This code may be used when TR says that families' educational background affects their attitudes.

5. Cause of death

Use this code when TR says that the cause of the patient's death (ie. Homicide, suicide, or natural causes, expected versus unexpected) has an impact on families' attitudes. Family may also discuss patient's placement or lack of placement on life support.

6. Knowledge of patient's donor registration status

Use this code when TR says that families' knowledge of the patient's wishes or donor registration status makes the decision easier or influences their attitudes.

7. Timing of request

Use this code when TR says that the timing of the request, for example, the call being so soon after the patient's death, affects the families' attitudes. TR might explain that families need more time to process the death and the timing of the call makes all the difference in whether families are open to listening to the request.

8. Stage of grief

Use this code when TR says that the families' stage of grief affects their attitudes. TR might refer to the denial or acceptance stages.

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9. How they cope/handle stress

Use this code when TR says that the way families cope with tragedy or how they manage stress has a great deal to do with their attitudes toward tissue donation.

10. Associating tissue donation with organ donation

Use this code when TR says that families' association of tissue donation with organ donation affects attitudes.

11. Knowledge about tissue donation

Use this code when TR says that families' knowledge about tissue donation affects attitudes.

12. Being registered donors themselves

Use this code when TR says that families who are registered donors are more likely to donate tissues.

13. Receptivity to new information/explanation

Use this code when TR says that a families' eagerness to learn about tissue donation or ability to process new information affects attitudes.

14. Having had a discussion about donation with patient

Use this code when TR says that families who have had a discussion about donation with patient or discussed the patient's wishes are more likely to donate tissues or have a better understanding of tissue donation.

15. Who around them is influencing their decision

Use this code when TR refers to family members or friends having an influence on families' decisions, beliefs, or attitudes.

16. Need to help others

Use this code when TR says that families' sense of altruism or want of helping others influences their attitudes.

17. Media/TV/Movies

Use this code when TR says that families' attitudes are affected by the media, shows on TV, the news, or movies (TR may discuss specific movies).

18. Other: _____

Use the "Other" code when you hear the TR give a reason or explanation as to why families confuse tissues with organs that is not captured in one of the codes above. Please summarize what code you think the statement should be.

19. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

20. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

15. What strategies do you use to overcome misconceptions?

This question relates to question 3 in the Interview Guide and may be a follow-up question or probe to it. This question is asking about the techniques or strategies that tissue requesters use during their requests with families to correct misconceptions.

1. Explain tissue donation to families in layman's terms

Use this code if TR says s/he describes tissue donation to families in simplistic terms or layman's terms in or to overcome misconceptions. TR may say, "sometimes we have to break it down even further."

2. Describe how reconstruction of the patient's body is done/prostheses

Use this code when TR says s/he describes how the patient's body is reconstructed after the procurement of tissues. The TR might refer to prostheses or talk about how the procurement team uses sutures to keep the body as intact as possible.

3. Describe the recovery of tissue from the patient

Use this code when TR says that s/he describes details of how the tissues are procured from the patient. For example, that a "thin layer of skin the thickness of a sheet of paper will be removed from your loved one", that the donation will be "like a surgical procedure", or that a "trained team of procurement specialists will treat your loved one's body with the utmost respect". TR may also explain timelines, such as "24 hours for tissues procurement."

4. Explain how the patient's appearance will not be altered

Use this code when TR says that s/he focuses on how the appearance of the patient's body will not be altered, that the patient will still look and feel the same as before the procurement of tissues. The TR might explain to families how the patient's body will not be mutilated or disfigured or that there will be no incisions to the face, contrary to many common misconceptions. TR may say, "his/her arm will still be there."

5. Focus on the benefits of tissue donation for others

Use this code when TR says s/he explains and/or emphasizes the benefits of tissue donation for others. For example, the TR might explain how one donor can help 100 individuals gain sight, walk again, or have improved qualities of life. The main focus of this code is that tissue donation helps others.

6. Clarify what the preclusions or rule-outs would be for donation

Use this code when TR says that s/he explains to families what the ineligibility criteria for tissue donation would be (i.e. history of certain medical conditions or diseases). The TR will usually use this strategy when families express concern over the suitability of the patient's tissues or ability to donate due to the fact that s/he had glaucoma or heart disease, etc.

7. Provide basic education

Use this code when TR says that they provide "basic education" to families as a strategy to overcome misconceptions. TR might "explain what tissue donation is" or

8. Explain the difference between organ and tissue donation

Use this code when TR says s/he explains the difference between tissues and organs or between tissue donation and organ donation. This may be due to the TR's perception that families are confused with what tissues are or need for clarification as to how it differs from organ donation. Another example of when the TR might use this strategy is when families do not understand what brain death is or say "I didn't think [patient] could donate because he's dead."

9. Explain the logistics of tissue donation

Use this code when TR says s/he explains the logistics of tissue donation to families. For example, the TR might explain how long the procurement process takes or how long the families have to make a decision to donate. Sometimes this strategy will be

used in response to families' concern over tissue donation delaying the funeral arrangements. Another time when this strategy is crucial is when the case requires an autopsy which involves many parties, time constraints, and procedures.

10. Ask the family to explain what they're thinking or why

Use this code when TR says s/he probes families into explaining out loud what their concerns are so as to better address them and have more open communication. This strategy may help build rapport between the TR and family and may also help families realize how they truly feel about tissue donation, which may more clearly guide them to the right decision.

11. Refer to the patient being on the registry

Use this code when TR says s/he brings up to families that the patient is on the registry. TRs use this strategy as many times families will support the patient's wishes.

12. Give personal stories

Use this code when TR says s/he uses personal narratives or draws on personal experiences to build rapport with families as well as to make the experience of donation more personal. TRs might explain that it helps families visualize who they will actually be helping instead of just people in general or strangers. TRs may have donated a loved one's tissues before and may mention it to families in order to console them and show that it was a positive experience.

13. Assure families that there will be no incisions on the face

This code is similar to code # 4, except this code should only be used when TR specifically says they tell families there will be no incisions to the face

14. Other: _____

Use the "Other" code when you hear the TR explain a strategy s/he uses to overcome misconceptions that is not captured in one of the codes above. Please summarize what code you think the statement should be.

15. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

16. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

15a. Do these strategies work? *This question refers to question 15 above and Q3 in the Interview Guide which asks "Do these strategies work?"*

1. Yes

Use this code when TR answers the question with a direct yes, definitely, absolutely etc.

2. No

Use this code when TR answers the question with a direct no.

3. It depends

Use this code when the TR replies with sometimes, maybe, it depends, etc. TR may also provide situations in which strategies worked and didn't; for example, "These strategies worked for issues of appearance, but never for those of religion." TR may

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also say, "Usually their worries will be dissuaded, but other times there's nothing you can tell them."

4. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

5. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

15b. How often do these strategies work? *This refers to Q15 above and Q3 of the Interview Guide.*

1. Never

Use this code when TR says the phrase, "strategies are never successful" or something similar.

2. Not often

Use this code if TR says "no" to the question, but also gives an example of when his/her strategies did work.

3. Sometimes

Use this code when the TR says "yes" to the question, but says "they work 50% of the time", "half of the families have a hard time converting", or "it depends".

4. Often

Use this code if TR says "usually" to the question, or "yes", but also gives an example of when his/her strategies do not work. For example, the TR might say, "Like my sister for example was a cornea recipient, but she and her husband still believe that if they sign up to be organ or tissue donors, not everything will be done to save them in the case of a life or death situation."

5. Always

Use this code if TR answers, "yes" to the questions and goes on to say that s/he has had 100% success with using those strategies.

6. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

7. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

16. What are families' positive initial reactions to the request for tissue donation? *This refers to Q5a of the TR Interview Guide which specifically targets positive reactions.*

1. They are excited to donate their loved one's tissues

Use this code when TR says families say, "We are excited to have this opportunity to donate".

2. They are familiar with the OPO and want to donate

Use this code when TR says families say, "We know who LifeNet is and we want to donate."

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- 3. They want to look at their loved one's license**
Use this code if TR says families want to refer to loved one's license to help make the decision to donate.
 - 4. They remember a conversation about tissue donation at the hospital/elsewhere**
 - 5. Use this code if TR says families have had a conversation about tissue donation previously somewhere else.**
 - 6. They are engaged in the conversation**
Use this code if the TR says families listen and ask questions, or are otherwise conversational and verbally interested.
 - 7. They mention that they know someone who has donated tissue or been a recipient**
Use this code if the TR says NOKs mention knowing a recipient of donation or if the NOKs themselves are recipients.
 - 8. They want to honor patient's giving personality**
Use this code if TR says families exclaim, "That's exactly what s/he would have wanted to do".
 - 9. They want us to take all we can**
Use this code if TR says families say, "Take what you need" or "take as much as possible for donation".
 - 10. They want us to help as many people as possible**
Use this code if TR says families say "the more you can take the better, so it can help more people" or "I hope we can help a lot of people with this donation".
 - 11. Other: _____**
Use this code when the TR mentions an initial positive reaction to the request for tissue donation other than the ones listed. Please summarize the statement you think the code should be.
 - 12. Don't know**
Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.
 - 13. NR/NA**
Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.
17. What are families' negative initial reactions to the request for tissue donation? *This refers to Q5c of the TR Interview Guide which targets the negative initial reaction.*
- 1. They simply say "No"**
Use this code if the TR has had a family that has simply said no and declined to go on with the request. TR may report this as an immediate or abrupt 'no'.
 - 2. They say the TR is a horrible person**
Use this code when TR says that s/he has had a family that has said that s/he is a horrible person for even bringing up tissue donation.
 - 3. They think the TR is trying to sell them something**
Use this code when TR says that s/he has had a family that has asked if s/he was a telemarketer or said, "What are you trying to sell me?".

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- 4. They will say why they don't think donation is a good idea**
Use this code if the TR says that s/he has had a family that has given a reason for thinking tissue donation is not a good idea.
 - 5. They are angry in general**
Use this code if TR has had a family that has been extremely negative about the process and expressed their anger through what they have said or their tone of voice.
 - 6. They are abrupt**
Use this code if TR has had a family that has given very short answers and cut off s/he during the request with their comments, questions, or simply hanging up.
 - 7. They are fearful of mutilation of their loved one's body**
Use this code if TR indicates that they have had a family who says they do not want their loved one to be cut on, abused, or mutilated in any way, shape, or form.
 - 8. Other: _____**
Use this code if TR mentions a families' initial negative reaction to the tissue donation request other than the ones listed. Please summarize the statement you think the code should be.
 - 9. Don't know**
Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.
 - 10. NR/NA**
Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.
18. What are families' other initial reactions to the request for tissue donation? *This refers to Q5b of the Interview Guide, where the TR observes unsure reactions or the family is undecided about donation.*
- 1. They can't make this decision (general)**
Use this code if TR mentions families saying that they can't make the decision without any specific reason why.
 - 2. They can't make this decision alone**
Use this code if the TR has had a family say that they cannot make the decision to donate alone and would like to discuss it with others first.
 - 3. Curious about tissue donation**
Use this code if TR has had a family say, "I am curious to learn more about donation" or asks more than the usual number of questions about donation.
 - 4. Surprised/caught off guard**
Use this code if TR has had a family say, "I am surprised you actually call people for this", "I'm sorry you caught me off guard, I haven't had time to process this yet", "this is the last thing I was thinking about", etc.
 - 5. Silence**
Use this code if TR has had a family remain silent for a long period of time and been overly delayed in answering questions about the request.
 - 6. Confusion**

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Use this code if TR has had a family say, "I'm sorry I don't understand what you mean" or "Could you explain that again, I'm still confused?"

7. They will ask a question

Use this code if TR has had a family that requests more information on the request

8. They will try to recall a discussion with their loved one

Use this code if TR has had a family member say, "I can't remember having a conversation with the patient" or "I don't think we ever discussed this"

9. Other: _____

Use this code if the TR has had a family express another initial reaction to the tissue donation request other than the ones listed. Please summarize the statement for which you think the code should be.

10. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

11. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

19. Issues/statements brought up by families who are initially favorable to the request?
This refers to Q16 above and the Probe of Q5a of the Interview Guide which asks "What issues stand out the most?"

1. They are surprised by the wide range of gifts

Use this code if the TR has had a family say, "Wow, I didn't know there were so many options to donate" or "I didn't know we could donate all these things".

2. They don't want the funeral to be delayed

Use this code if the TR has had a family say, "I hope this won't delay the funeral" or if they ask, "Will this delay our arrangements, because that would be bad?"

3. They have questions about the patient's appearance

Use this code if the TR has had a family ask, "Will this donation change my loved ones appearance?"

4. They want to know if they can still have a viewing

Use this code if the TR has had a family ask, "Can we still have a viewing if we donate?" or "Can we have an open casket?"

5. Will they be able to meet the recipient(s)

Use this code if TR has had a family ask about meeting the recipient(s) of their gift of donation. They could ask whether it were possible or allowed.

6. Logistics/timing of completing paperwork

Use this code if TR has had a family express concern about how the paperwork was to be completed or when the paperwork had to be done.

7. They are overwhelmed with the length of paperwork

Use this code if TR has had a family say they can't handle the amount of necessary paperwork at the moment.

8. They are put off by the invasiveness of the med/soc

Use this code if TR has had a family say that the medical/social history is too invasive or personal.

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- 9. They think they have to go to the hospital to give consent**
Use this code if TR has had a family ask if they had to go to the hospital in order to give consent to donate.
 - 10. Will it cost the family any money to donate**
Use this code if TR has had a family ask if it would cost them anything to donate tissues.
 - 11. The time it will take to recover the tissues**
Use this code if TR has had a family inquire about the length of time needed to recover the tissues for donation.
 - 12. How soon they can see their loved one**
Use this code if TR has had a family ask how soon they could see their loved one after the recovery of tissues.
 - 13. They want tissue donation to be explained in more detail**
Use this code if TR has had a family ask for the tissue donation process to be explained more clearly.
 - 14. They want their loved one to live on through donation**
Use this code if TR has had a family express that they wanted their love one to live on through donation or leave a good legacy.
 - 15. None, they just listen**
Use this code if TR has had a family simply listen to the explanation of the donation process without asking any questions or expressing concerns.
 - 16. Other:** _____
Use this code if TR has heard an issue/statement by family who was initially favorable for tissue donation other than those listed.
 - 17. Don't know**
Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.
 - 18. NR/NA**
Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.
20. Issues/statements brought up by families who are initially unsure to the request? *This refers to Q18 above and the Probe of Q5b of the Interview Guide where the TR observes specific reasons of why the family is unsure of the request.*
- 1. They are unsure of their loved one's wishes**
Use this code if TR has had a family say that they weren't sure of what their loved one's wishes were.
 - 2. Appearance**
Use this code if TR has had a family question if their loved one's appearance would be altered.
 - 3. Time**
Use this code if TR has had a family say there won't be enough time for tissue donation.
 - 4. Unsure of ability to donate if not cremating patient**

Use this code if TR has had a family say they doubt they will be able to donate if they are not having a cremation.

5. Unsure if cremation is possible with prosthetics replacing the tissues

Use this code if TR has had a family doubt possibility of donation because the prosthetics will affect cremation.

6. They want the whole family's opinion about donation

Use this code if TR has had a NOK want to get the rest of the family's opinion before making the decision to donate.

7. Can they still donate 'organs' since patient is dead

Use this code if TR says they have had a family ask if their loved one can still donate organs even if s/he is deceased.

8. They want to know if a funeral is still possible

Use this code if TR has had a family ask if a funeral is still possible despite tissue donation.

9. Concern about loved one having another surgical procedure

Use this code if TR has had a family express concern about their loved one undergoing another surgical procedure.

10. They don't want patient to go through any more trauma or suffering

Use this code if TR has had a family say that they do not want their loved one to go through any more pain and suffering.

11. They just want it to be all done with

Use this code if TR has had a family just want the whole ordeal to be over.

12. Can they still have a viewing

Use this code if TR has had a family ask if they could still have a viewing even after tissue donation.

13. They question the suitability of patient's tissues to donate

Use this code if TR has had a family question their loved one's tissues suitability for donation.

14. They delay making a decision because they don't want to say no

Use this code if TR mentions that some families intentionally delay the decision making process because they want to help and don't want to say no.

15. They don't want patient cut on

Use this code if TR has had a family say they do not want their loved one to be cut on, sliced up, mutilated, or disfigured.

16. They don't want to think about it at that time

Use this code if TR has had a family express that they could not think about such a thing at such a time as this.

17. They want their loved one to have what they came into the world with

Use this code if TR has had a family say they wanted their loved one to exit the world with what they entered it with.

18. Disbelief

Use this code if TR has had a family say the couldn't believe that their loved one had died and couldn't contemplate tissue donation until it sank in.

19. They feel overwhelmed with all the tasks/duties surrounding patient's death

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Use this code if TR has had a family say they are burdened by all the tasks that have suddenly come up as a result of their loved one's death.

20. They want/need more information

Use this code if TR has had a family ask for more information about the tissue donation process.

21. Other: _____

Use this code if TR mentions an issue/statement by families that were initially unsure to the request other than those listed.

22. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

23. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

21. Issues/statements brought up by families who are initially unfavorable to the request?
This refers to Q17 above and the Probe of Q5c of the Interview Guide which targets negative reactions.

1. Their loved one has suffered enough

Use this code when TR says that families feel as though the patient has been through or suffered enough and they don't want to disturb them anymore, they just want their loved one to rest in peace.

2. They don't want their loved one cut on

Use this code when TR says that families say that they don't want their loved one to be cut or mutilated.

3. Their loved one can still feel what's going on

Use this code when TR says that some families believe that their loved one is still alive in some way, shape, or form.

4. They are too emotional to engage in conversation

Use this code when TR says that families have become too emotional to carry on the request, become un-respondent, crying uncontrollably, etc.

5. Simply "no"

Use this code when TR says families simply decline to donate without any apparent reason.

6. Their loved one didn't sign up to be a donor

Use this code when TR says families say, "S/he didn't sign up to do this" or "I don't believe it was marked on his/hers license"

7. They don't want to delay the funeral arrangements

Use this code when TR says families think that donation will delay the funeral arrangements.

8. It's a terrible time to ask

Use this code when TR says they have had families who have said, "Your timing is bad", "I can't discuss this right now, it's too bad", or "It's a terrible time for you to be calling, it just happened".

9. They never discussed donation with loved one

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Use this code when TR says that they have had families that say, "I have not talked about donation with the patient"

10. It's against patient's religion

Use this code when TR says that families have said that tissue donation was against the deceased religion.

11. It's against family's religion

Use this code when TR says that families have said that tissue donation is against their religion.

12. It's not right

Use this code when TR says that they have had a family who believes that tissue donation is not the right thing to do.

13. They want to make the same decision they did with another family member

Use this code when TR says that they have had a family that has mentioned making a decision to or not to donate with another family and would like the same thing for this loved one.

14. They remember the negative experience at the hospital

Use this code when TR says families mentioned a negative experience at the hospital that has negatively influenced their decision to donate.

15. They remember the negative experience at the ME's office

Use this code when TR says families have referenced a bad experience at the ME's office that has negatively influenced their decision to donate.

16. They remember the negative experience with law enforcement

Use this code if TR says that a family has said they remember a bad experience with law enforcement.

17. They are against donation in general

Use this code if TR has had a family that has been against donation in general without listing any specific reasons.

18. Viewing

Use this code if the TR has had a family that thinks donation will affect the physical viewing

19. Time constraints

Use this code if the TR has had a family that believed that they would not have enough time between donation and funeral arrangements

20. They are angry with their loved one

Use this code if the TR says that a family is furious with their loved one before their death or unto the time of death

21. They are disappointed with their loved one

Use this code if the TR has had a family that was upset with their loved one

22. Other: _____

Use this code if the TR mentions statements/issues that have been raised by families that were initially unfavorable for donation other than the ones listed. Please summarize the statement for which you think the code should be.

23. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

24. NR/NA

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Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

22. Do you see much public education on tissue donation? *This refers to Q6 of the TR Interview Guide which asks "Do you see much public education on tissue donation?"*

1. Yes, a lot

Use this code if the TR says they have seen a lot of public education on tissue donation and lists some of these examples.

2. Yes, some

Use this code if the TR says they have seen a few examples of public education on tissue donation and lists one or two of these examples. TR may also say, "not much."

3. No

Use this code if the TR says they have not seen any forms of public education on tissue donation. TR may also reply: "not really" or "not anything specific to donation".

4. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

5. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

23. What public education on tissue donation do you see? *This refers to the Probe of Q6 of the TR Interview Guide.*

1. Community events where staff from LifeNet do presentations

Use this code if TR has said s/he has heard of or attended a community event where LifeNet staff made presentations.

2. Signing up on the donor registry

Use this code if TR has said s/he has seen people sign up on the donor registry. TR may mention the DMV or driver's license forms plainly asking, "Do you want to be a donor".

3. Driver's education programs

Use this code if TR has said s/he has seen information concerning tissue donation in driver's education programs.

4. A poster at the DMV

Use this code if TR has said s/he has seen a poster at the DMV containing information about tissue donation.

5. A discussion at the DMV

Use this code if TR has said s/he has heard a discussion about public education concerning tissue donation at the DMV.

6. A pamphlet at or from the DMV

Use this code if TR has said s/he has seen or received a pamphlet at the DMV concerning tissue donation.

7. In school as an SOL requirement

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Use this code if TR has said s/he has seen or heard of a school using information about tissue donation as an SOL requirement.

8. At a concert near LifeNet headquarters

Use this code if TR has said s/he has attended or heard on of a concert near LifeNet headquarters.

9. Nothing outside of LifeNet's (or people in the industry) efforts

Use this code if TR has said s/he hasn't seen or heard any public education about tissue donation other than from LifeNet or others in the industry.

10. By word of mouth from friends or family who registered as a donor

Use this code if TR has said s/he has heard about tissue donation from friends or family who are registered donors.

11. A bumper sticker on someone's car (usually about organ donation)

Use this code if TR has said s/he has seen or heard of a bumper sticker about tissue and/or organ donation.

12. None specifically on tissue donation, only organ donation

Use this code if TR has said s/he hasn't seen any public education about tissue donation, only organ donation.

13. Other: _____

Use this code if TR has said s/he has seen a form of public education on tissue donation other than those listed.

14. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

15. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

24. What do you think would be the most important message(s) to include in an educational intervention about tissue donation for the general public? *This refers explicitly to Q7 of the TR Interview Guide.*

1. What the tissues can do

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is what the tissues can be used for.

2. Tissue donation does not affect the appearance of your loved one

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that it does not alter the appearance of their loved one.

3. Tissue donation allows you to leave a legacy of your loved one behind

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that it provides a way to leave a legacy of your loved one behind.

4. Something good that can come out of something bad

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that it allows something good to come out of a bad situation.

5. The number of individuals that can be helped by one tissue donor

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that it is possible for the donation to help more than one person.

6. Tissue donation can be life-saving/life-enhancing

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that it could possibly save someone's life or enhance it.

7. Distinguishing between organ and tissue donation

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that there is a difference between organ and tissue donation.

8. Showing how organ and tissue donation complement each other

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that organ and tissue donation complements each other.

9. Tissue donation improves health

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that it can improve someone else's health.

10. It really impacts lives - Put a face with a story and a situation

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that the gift can impact lives and that there should be a face with each story and situation to make it more personal.

11. How certain tissues help people walk

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that it can help others walk again.

12. Tissues can give individuals the ability to hold someone

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that it can give individuals the ability to hold someone and have a personal connection again.

13. Tissues can give individuals the ability to look better

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that it can improve someone's appearance.

14. How cornea donation can help 2 people see in 2 weeks

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that it can help two different people see in as little as two weeks.

15. The short-term benefits of tissue donation

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Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation is that there are a number of short-term benefits associated with donation as well.

16. Statistics on the need for tissue donors (ie.# people waiting for tissues)

Use this code if TR believes that the most important message that should be included in an education intervention about tissue donation are statistics that show the importance of tissue donation and the need for an increased number of donors.

17. Other: _____

Use this code if TR mentions an important message that should be included in an education intervention about tissue donation for the general public other than those listed.

18. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

19. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

25. Do you think an educational message about tissue donation should be separate from organ donation? *This refers to Q6 of the Interview Guide as well as Q8 because specifically targeting tissue donation could increase consent rates.*

1. Yes

Use this code if the TR believes that educational messages about tissue donation should be separate from those about organ donation.

2. No

Use this code if the TR believes that they believe educational messages about tissue donation should be presented together with those about organ donation. TR may suggest grouping tissue donation with organ donation to use the positivity and support surrounding organ donation to benefit tissue donation.

3. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

4. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

26. What group(s), if any, would you target to educate about tissue donation? *This refers to the Probe of Q7a which specifically asks about targeting certain groups.*

1. Younger generation (<30) (Go to Q26a)

Use this code when TR wants to target people less than 30 years old, TR may say "younger crowd," "young adults," "college kids"

2. Middle age (30-60) (Go to Q26b)

Use this code when TR makes reference to target "mature adults", TR might make reference to "parents"

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3. Older generation (>60) (Go to Q26c)

Use this code when TR want to target older people and makes references to "grandparents" or "retired"

4. Hispanic community (Go to Q26d)

Use this code when TR wants to target specifically the Hispanic community. TR may say things like "Spanish"

5. African American community (Go to Q26e)

Use this code when TR wants to target specifically the African American community

6. Spouses (Go to Q26f)

Use this code when TR wants to target specifically the spouse of the loved one

7. Parents of young children (Go to Q26g)

Use this code when TR wants to target specifically the parents of young children

8. Children (Go to Q26h)

Use this code when TR wants to target specifically the children. TR may say "kids"

9. Everyone (Go to Q26i)

Use this code when TR wants to target the whole general public

10. Other (Go to Q26j): _____

Use this code to summarize why TR would target the other groups if different than other reasons listed.

11. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

12. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

26a. Why would you target the younger generation?

1. They don't know enough about it

Use this code if TR feels that families are uneducated about, or lack knowledge about tissue donation.

2. They are the healthiest donors

Use this code when the TR says the younger generation is "healthy" or "fit"

3. They become the decision-makers for tissue donation

Use this code when the family expresses that the younger generation should be targeted because they will ultimately become the decision-makers for the donation of others (i.e. their parents, siblings, or children).

4. They are starting to formulate their own attitudes towards donation

Use this code when TR believes that the younger generation are still at the stage of coming up with their own beliefs

5. They are best suited to have discussions with their family members

Use this code when TR believes that the younger generation are still in the stage of discussing things with their family members for approval

6. Other: _____

Use this code to summarize why TR would target the younger generation if different than other reasons listed.

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7. **Don't know**

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

8. **NR/NA**

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

26b. Why would you target the **middle age**?

1. **They don't know enough about it**

Use this code if TR believes that middle age is less informed about tissue donation

2. **They don't realize what they checked off on their license**

Use this code if TR believes that middle age are less likely to pay attention to detail when they give consent during the time of licensing

3. **They experience the most despair upon death of a loved one**

Use this code if TR believes that middle age experience the most loss and s/he may say they will a lot during their time of living

4. **Their attitudes are more strongly engrained**

Use this code if TR says s/he middle age target have knowledge that is deeply-rooted or embedded

5. **Other:** _____

Use this code to summarize why TR would target the middle age group if different than other reasons listed.

6. **Don't know**

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

7. **NR/NA**

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

26c. Why would you target the **older generation**?

1. **They don't know enough about it**

Use this code when TR says the older generation is less informed on tissue donation

2. **They have misconceptions about suitability of tissues**

Use this code when TR says s/he the older generation thinks their tissues have worn out, or may not be of use

3. **They don't understand what tissue donation can do for others**

Use this code if TR believes that the older generation is not aware of the benefits on tissue donation

4. **They make up a large percentage of actual tissue donors**

Use this code if TR believes that older generation are the most important targets of tissue donation

5. **Other:** _____

Use this code to summarize why TR would target the older generation if different than other reasons listed.

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6. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

7. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

26d. Why would you target the **Hispanic community**?

1. They don't know enough about it

Use this code if TR believes that this community may not have a lot of education on the topic

2. They are neglected in society due to language barrier

Use this code if TR believes that society limits education on tissue donation due to language barrier

3. They have no exposure to tissue donation

Use this code if TR believes that this community may not have the opportunity to be in proximity to tissue donation information

4. Other: _____

Use this code to summarize why TR would target the Hispanic community if different than other reasons listed.

5. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

6. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

26e. Why would you target the **African American community**?

1. They don't know enough about it

Use this code if TR believes that this community may not have a lot of education on the topic

2. They have no exposure to tissue donation

Use this code if TR believes that this community may not have the opportunity to be in proximity to tissue donation information

3. There is much confusion between organ and tissue donation

Use this code if TR believes this community has misconceptions between organ and tissue donation

4. They don't trust that organs/tissues will be allocated fairly

Use this code if TR believes this community may not entrust in organ/tissue donation because of their lack of knowledge

5. They believe tissues will be taken while loved one is still alive

Use this code if TR believes because of lack of knowledge, this community thinks that tissue is legally allowed to be taken while loved one is still alive

PUBLIC'S ATTITUDES TOWARD TISSUE DONATION

6. **They believe not everything will be done to save loved one if donor card is marked**

Use this code if TR believes this community is misinformed on the logistic process of tissue donation, therefore donation will be bias to their loved one

7. **There is a lack of trust in the medical field/research in general**

8. **Other:** _____

Use this code to summarize why TR would target the African American community if different than other reasons listed.

9. **Don't know**

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

10. **NR/NA**

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

26f. Why would you target **spouses**?

1. **They are most emotional at time of a loved one's death**

Use this code if TR believes targeting spouses during this emotional state of mind would make them make a quicker response so that it won't affect the time frame of donation

2. **They comprise the majority of legal next of kin**

Use this code if TR believes targeting spouses would eliminate the one degree to the second nest of kin

3. **They can inform their significant other of their wishes**

Use this code if TR believes targeting spouses would make donation go more smoothly because it may have been discussed between their loved one

4. **They are most likely to follow-through with their significant other's wishes**

Use this code if TR believes the spouse will more likely support their significant other's wishes

5. **Other:** _____

Use this code to summarize why TR would target spouses if different than other reasons listed.

6. **Don't know**

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

7. **NR/NA**

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

26g. Why would you target **parents (of young children)**?

1. **They are most likely to donate**

Use this code if TR believes targeting parents would make the parents look at things from other people's perspective, therefore they will donate

2. **They need to make sense of death**

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Use this code if TR believes targeting parents would mean parents will try to make a death count for something good

3. They want their loved one to live on

Use this code if TR believes targeting parents would assure them that their loved ones will forever be around them

4. Heart valves, which typically come from young children, are in demand

Use this code if TR believes that target parents would be easier since they would have more knowledge of the health demands than children would

5. Other: _____

Use this code to summarize why TR would target the parents (of young children) if different than other reasons listed.

6. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

7. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

26h. Why would you target **children**?

1. So they can educate their parents

Use this code if TR believes children are more prone to get donation information first so that it can be transferred to their parents

2. They are most receptive to new information

3. Other: _____

Use this code to summarize why TR would target children if different than other reasons listed.

4. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

5. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

26i. Why would you target **everyone**?

1. Everyone can benefit

Use this code if TR believes that tissue donation is valuable for anyone of any age and race

2. Not enough information out there in general

Use this code if TR believes that targeting everyone will help because information is limited in the real world

3. Other: _____

Use this code to summarize why TR would target everyone if different than other reasons listed.

4. Don't know

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Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

5. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

26j. Why would you target _____(specify_____)?

1. Other: _____

Use this code if TR wants to target a group other than those listed to summarize why they would do so.

2. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

3. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

27. Through which medium do you think tissue donation should be publicized? *This refers to Q8 of the Interview Guide which asks about educating the public. These methods could increase consent rates.*

1. Billboards

Use this code if TR believes that billboard advertisement is the best way to get more information about donation to the public

2. TV commercials

Use this code if TR gives example of broadcast or might name some examples of commercials

3. On TV shows

Use this code if TR gives examples of specific television show

4. Brochures

Use this code if TR talks gives examples of handouts to be passed out during conferences, games, doctor's office

5. Internet

Use this code if TR gives examples of different websites such as YouTube for video, ads on different sites, Google, etc. .

6. A book to read while waiting at the DMV

Use this code if TR says things such as "sitting in the DMV..."

7. Other: _____

Use this code if TR says that tissue donation should be publicized through a medium other than those listed.

8. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

9. NR/NA

PUBLIC'S ATTITUDES TOWARD TISSUE DONATION

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

28. Do you think that educating the public about tissue donation would help to increase consent rates? *This question directly refers to Q8 of the Interview guide concerning education and consent rates.*

1. Yes

Use this code if TR says that they believe that educating the public about tissue donation would help to increase consent rates. TR may simply say that families will "be more open to it" after education.

2. No

Use this code if TR says that they believe that educating the public about tissue donation would not help to increase consent rates.

3. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

4. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

28a. Probe to Q28, Why?

1. It will make the decision much easier later on

Use this code if the TR believes education will make families more open to donation, prepare them for the tissue request, or smooth out the consent process when it comes time for them to donate a loved one's tissues.

2. Families will be able to have a more informed consent

Use this code if the TR believes that education will make more families knowledgeable to give correct consents to donation as well as make the process go by smoothly

3. Families will be better educated on the subject

Use this code if the TR believes that education on donation will make families have a better understanding of the donation process

4. Families will be more comfortable with the topic through previous exposure

Use this code if the TR believes that education will make families more familiar with the topic and have time to process the information before the actual time of donation

5. Families will have a greater willingness to donate

Use this code if the TR believes that education will make families feel eager to donate because of their prior knowledge

6. Families can distinguish between organs and tissues

Use this code if the TR believes that education will make families more up to date with the information on donation and knowing the difference between organ and tissue donation

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7. Families will understand other ways to help others aside from organ donation

Use this code if the TR believes that education will help families understand that there are different options to take besides organ donation

8. Families will associate tissue donation with saving lives

Use this code if the TR believes that education will help families open up to the possibility of saving lives and that itself is a gift

9. Families will have less fears about tissue donation

Use this code if the TR believes that education will help families have a better understanding of donation and eliminate negative thoughts about donation

10. It will prepare families for a future request over a telephone call

Use this code if the TR believes that education will help families practice other types of ordeals that can be asked of them in the future

11. It will encourage more discussions

Use this code if the TR believes that education will help families come up with more questions to engage in the process

12. Other: _____

Use this code if the TR believes that education will help families with other ways than what is listed above

13. Don't know

Use this code when TR says s/he doesn't know, or doesn't know how to answer the question.

14. NR/NA

Use this code when TR does not answer the question, the question is not asked, or if it is not an applicable question for this particular TR or interview.

DATA ENTRY INSTRUCTIONS

1. Use Qualtrics online software to enter codes into the data entry form entitled, "Tissue Requester Coding Instrument".
2. Make sure to enter the correct Case Number, Date, and Coder's Initials written at the top of the paper instrument.
3. Use the text boxes to write in answers where indicated, including the text boxes for "other" responses.
4. When you are finished entering a case, please clearly write "Entered by" and your initials along with the date you entered the case at the top of the instrument in pen.

PUBLIC'S ATTITUDES TOWARD TISSUE DONATION

Appendix D

Entered By:

--

Date Entered:

--

Case #:

--

Coder's Initials:

--

Date Coded:

--

Understanding the Public's Attitudes toward Tissue Donation FDM Coding Instrument

Please mark all codes that apply unless otherwise noted.

1. NOK's affective-based attitudes.

A. Positive:

- 1A ☐ NOK is excited
- 2A ☐ NOK feels good
- 3A ☐ NOK feels grateful
- 4A ☐ Other _____
- 5A ☐ None

B. Negative:

- 1B ☐ NOK feels guilty
- 2B ☐ "Ick" factor
- 3B ☐ NOK feels that tissue donation is barbaric
- 4B ☐ NOK feels tissue donation is offensive
- 5B ☐ Request too difficult to understand at raw moment in life
- 6B ☐ NOK does not want patient's body to be touched
- 7B ☐ NOK does not want patient's body to be cut on
- 8B ☐ NOK/family has been through enough already
- 9B ☐ Patient has been through enough already
- 10B ☐ NOK wants to remember patient the way s/he was
- 11B ☐ Details of tissue donation not important
- 12B ☐ Tissue donation conjures negative imagery
- 13B ☐ NOK feels that donating tissues is going too far
- 14B ☐ Other _____
- 15B ☐ None

2. NOK's behavior-based attitudes.

A. Positive:

- 1A ☐ NOK is a registered donor

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- 2A ☐ NOK supports patient's wishes
- 3A ☐ NOK had a discussion about donation with patient
- 4A ☐ NOK told patient tissue donation was a good thing to do
- 5A ☐ NOK has discussed donation with family
- 6A ☐ NOK has discussed donation with friends
- 7A ☐ NOK has discussed donation with others
- 8A ☐ NOK has donated before
- 9A ☐ NOK was/is involved with donation in some way (Specify how: _____)
- 10A ☐ Other _____
- 11A ☐ None

B. Negative:

- 1B ☐ NOK told patient tissue donation was NOT a good thing to do
- 2B ☐ NOK is NOT a registered donor
- 3B ☐ NOK does NOT support patient's wishes
- 4B ☐ NOK has discussed donation with family
- 5B ☐ NOK has discussed donation with friends
- 6B ☐ NOK has discussed donation with others
- 7B ☐ Other _____
- 8B ☐ None

3. NOK's cognitive-based attitudes.

A. Positive:

- 1A ☐ NOK believes it's the right thing to do
- 2A ☐ It's better the tissue is used than unused
- 3A ☐ Patient is just a body, not a person
- 4A ☐ NOK believes tissue donation saves lives
- 5A ☐ NOK believes tissue donation helps people
- 6A ☐ Other _____
- 7A ☐ None

B. Negative:

- 1B ☐ Donation will alter patient's appearance
- 2B ☐ There will be nothing left of patient
- 3B ☐ NOK believes patient is still alive in some way
- 4B ☐ NOK believes tissue donation will delay the funeral
- 5B ☐ NOK believes tissue donation will affect the viewing
- 6B ☐ Patient's body will not be treated with respect
- 7B ☐ NOK believes that patient's tissues are not suitable for donation
- 8B ☐ NOK believes that tissue donation will cost him/her money
- 9B ☐ NOK believes that tissue donation is only possible with cremation
- 10B ☐ NOK thinks s/he has to go to the hospital to donate patient's tissues

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- 11B ☐ NOK believes that the patient will not be able to be buried
- 12B ☐ Not enough medical attention will be provided to patient
- 13B ☐ Patient is too sick to donate/has too many medical conditions
- 14B ☐ Rich people get organs/tissues faster
- 15B ☐ Patient's body parts will be taken
- 16B ☐ Tissue donation does NOT save lives
- 17B ☐ Tissue donation industry is all profit-driven
- 18B ☐ Tissue donation industry is sinister and manipulative
- 19B ☐ Tissue donation is not possible because patient is dead
- 20B ☐ Tissues will be wasted
- 21B ☐ Patient is too old to be on registry/donate
- 22B ☐ NOK will not be able to see patient again
- 23B ☐ Patient will not feel the same
- 24B ☐ Patient will not look the same
- 25B ☐ Patient wanted to go out of the world the way he came into it
- 26B ☐ NOK wants the patient to go out of the world the way he came into it
- 27B ☐ It's against patient's religion
- 28B ☐ It's against NOK's religion
- 29B ☐ Eyes are the windows to the soul
- 30B ☐ Patient needs all his/her parts to get into heaven
- 31B ☐ NOK thinks the patient's tissues will not do any good
- 32B ☐ Other _____
- 33B ☐ None

4. NOK's OTHER Attitudes.

- 1 ☐ NOK wants to spare others the grief s/he is experiencing
- 2 ☐ NOK feels that tissue donation is not necessary
- 3 ☐ NOK is against patient having another surgical procedure
- 4 ☐ NOK does not want to prolong the consent process
- 5 ☐ Other _____
- 6 ☐ None

5. Counter-arguments.

- 1 ☐ Prostheses will be put in place of bone to keep the body's shape
- 2 ☐ Tissue donation can improve the health of others
- 3 ☐ Tissue donation can save lives
- 4 ☐ Explanation of the possible gifts
- 5 ☐ Tissue donation is a way of honoring patient
- 6 ☐ Patient can still donate with a medical history
- 7 ☐ Patient is on the registry
- 8 ☐ Tissues can have a longer life span than organs
- 9 ☐ There's a variety of tissues that can be donated
- 10 ☐ It's not the eye, it's the cornea or the contact lens portion of the eye
- 11 ☐ Tissue donation is different than organ donation

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- 12 ☐ Tissue donation still possible after patient has died
- 13 ☐ The tissues are procured in a similar way as a surgery
- 14 ☐ The patient will be treated with respect
- 15 ☐ The paperwork is done over the phone
- 16 ☐ Donation is possible whether having a funeral, viewing, or cremation
- 17 ☐ Redirect NOK to clergymen
- 18 ☐ There is no cost associated with tissue donation
- 19 ☐ Other _____
- 20 ☐ N/A

6. Did the NOK have different attitudes after receiving information/counter-arguments?

- 1 ☐ Yes
- 2 ☐ No

7. Which counter-argument changed the NOK's attitudes?

- 1 ☐ Prostheses will be put in place of bone to keep the body's shape
- 2 ☐ Tissue donation can improve the health of others
- 3 ☐ Tissue donation can save lives
- 4 ☐ Explanation of the possible gifts
- 5 ☐ Tissue donation is a way of honoring patient
- 6 ☐ Patient can still donate with a medical history
- 7 ☐ Patient is on the registry
- 8 ☐ Tissues can have a longer life span than organs
- 9 ☐ There's a variety of tissues that can be donated
- 10 ☐ It's not the eye, it's the cornea or the contact lens portion of the eye
- 11 ☐ Tissue donation is different than organ donation
- 12 ☐ Tissue donation still possible after patient has died
- 13 ☐ The tissues are procured in a similar way as a surgery
- 14 ☐ The patient will be treated with respect
- 15 ☐ The paperwork is done over the phone
- 16 ☐ Donation is possible whether having a funeral, viewing, or cremation
- 17 ☐ Redirect NOK to clergymen
- 18 ☐ There is no cost associated with tissue donation
- 19 ☐ Other _____
- 20 ☐ N/A

8. What attitudes changed?

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9. Other external factors.

- 1 ☐ Funeral director said something
- 2 ☐ Hospital/Other experience
- 3 ☐ Not able to cope/handle stress
- 4 ☐ Never heard of tissue donation before
- 5 ☐ Logistics
- 6 ☐ Med/soc too long
- 7 ☐ Med/soc too personal
- 8 ☐ Other _____
- 9 ☐ N/A

10. Did NOK make any reference to or comment about TV, Movies, or Media?

- 1 ☐ Yes, it was positive
- 2 ☐ Yes, it was negative
- 3 ☐ Yes, but it was neither positive nor negative
- 4 ☐ No

11. Did NOK confuse tissues with organs?

- 1 ☐ Yes
- 2 ☐ No
- 3 ☐ No basis to tell

12. If s/he confused tissues with organs, how did s/he associate it?

- 1 ☐ NOK associated tissues with organs in a positive way
- 2 ☐ NOK associated tissues with organs in a negative way
- 3 ☐ NOK associated tissues with organs in neither a positive nor a negative way
- 4 ☐ N/A

Other/Notes/Comments

PUBLIC'S ATTITUDES TOWARD TISSUE DONATION

SECONDARY DATA SOURCE: AUDIOFILES OF REQUESTS WITH FAMILIES

Lindsey Kurland
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Virginia Commonwealth University

CODING RULES

To All Coders for this Study:

It is important for you to be extremely familiar with this coding manual before coding audiofiles of tissue donation requests. Please carefully review the following preliminary rules for coding:

1. For each case you code, please print out a copy of the coding instrument and enter the case number, your name, and the date you coded the case. When entering this data, please write "data entered by: (your name)" and the date the case was entered at the top.
2. For each code you select, please make sure to fill in the box/circle beside the code completely (as your paper instruments will be scanned through a computer software program and may not be recognized if not notated correctly).
3. In places where there is a line (like this _____), please write the exact statement made by the next-of-kin (NOK) that indicates what you are coding for.
4. Please mark all codes that apply for each case. Pay attention to marking the appropriate codes for statements made by NOK. There may be more than one code for some statements and no codes that apply for other statements. If you come across an important concept when coding audiofiles that is not captured in one of the codes provided in the instrument please mark the "Other" box and succinctly write in that code.
5. There may be some cases where someone other than the NOK fields the call for the NOK. If this person acts as a relay or as a proxy to the NOK code as if this person is the NOK.
6. When more than one NOK speak with the TR, code all people connected to NOK who speak with TR as one NOK or as a conglomerate.
7. If you come across a case where no attitudes can be discerned and the NOK simply says "No" to the request for tissue donation, do not code this case and label it with "Just No" at the top of the instrument. New cases that contain at least one code-able attitude will be re-sampled in place of these "Just No" cases.
8. When you have a question regarding the use of a code, please refer to this manual as descriptions for codes should be able to guide you. Reading the descriptions is the key to choosing the appropriate codes as some of the codes seem very similar but are actually slightly nuanced and have different meanings. If you are still stuck, put a star next to the question or code you are unsure of and bring that question to our weekly team meetings to discuss.
9. Once you've coded a case, you are not necessarily done with it. You will be responsible for making appropriate changes to coding instruments as needed (i.e., changing one code for another, adding a new code, deleting a code). Usually any

revisions will take place after new information emerges at our weekly meetings or after the coding manual has been updated or revised.

GENERAL CONCEPTS AND DEFINITIONS

Attitudes

In the realm of psychology, attitudes are comprised of a person's beliefs and feelings toward an attitude object. Attitudes may be favorable, unfavorable, or neutral. A person may have many different attitudes which make up his/her overall attitude toward an attitude object.

Attitude Object

An attitude object is a person, place, event, or thing for which a person's attitudes are directed towards. In this case, the attitude object is tissue donation.

Tripartite Model of Attitude Structure (ABC Model)

This theory posits that attitudes are comprised of three distinct components: affective, behavioral, and cognitive. The coding scheme for this study is based on this theory.

Affective Component

This component focuses on attitudes rooted in an emotional response. The affective component reflects more of an immediate feeling and is not always logical. Usually an affective attitude will be elicited immediately after an attitude object (ie. tissue donation) is presented. Often the affective component will be displayed through statements expressing how a person "feels".

Behavioral Component

This component is based on a person's past behaviors with respect to the attitude object. Often the behavioral component will be displayed through statements expressing what a person "has done" or "will do". Behavioral statements reflect what a person's intentions are or past behaviors have been.

Cognitive Component

This component reflects a person's thoughts or beliefs which may be based on what they perceive as factual. Often times this component of attitudes is elicited as stereotypes, false beliefs, or misconceptions. Other times this component is present when a person is rationalizing his/her beliefs or questioning or trying to understand something. Often the cognitive component will be displayed through statements expressing what a person "thinks" or "believes".

CODING INSTRUCTIONS

The codes in the instrument included here are in the same order and in **bold**. Descriptions for these codes are written beneath the bolded codes and are in *italics*.

1. NOK's affective-based attitudes.

A. Positive: *Positive affective codes reflect the NOK having affective attitudes that are in favor of tissue donation in some way.*

1A. NOK is excited

Use this code when NOK is very happy about donating patient's tissues. NOK may say, "This is such a wonderful opportunity" or "This is so great, more people should do it." This code has a greater degree of positive emotion towards tissue donation than code 2A "NOK feels good."

2A. NOK feels good

This code should be used when NOK makes a statement referring to how s/he feels positively towards donating their loved one's tissues. NOK has to make some positive assertions about the donation process/tissue request as a whole. This doesn't necessarily mean that they must agree with everything or even end up donating, but they have to exhibit a greater positive attitude (ie. if the NOK says, "I feel a little better now that I made this decision"). Use this code when over the course of the conversation it seems that the NOK has found a sense of relief about their decision. NOK has to state their reason or express more than a simply, "yes I would like to donate". Statements this code can be used for include, "I feel satisfied with donating John's tissues" or "I feel at peace with my decision"; "We want to do this because..."; "Yes, we would like to..."; "This is a great/good idea/thing,"; "...[pause].....Yes. Let's do this" [This example depends on the context. In this case, this statement was made after the TR initially tells the NOK about the donation process]; "I've discussed it at length and I want to respect my husband's/wife's wishes, but thank you for your time. I think tissue donation is a great thing, but I have to decline." Scenarios of when the coder should clue in to using this code are: the NOK calls or calls back TR about donation instead of visa versa or the NOK has expressed interest in donation to hospital staff or other organ/tissue procurement staff and TR calls in response to interest.

3A. NOK is grateful

This code should be used when NOK expresses appreciation that this opportunity exists for the family, whether to help them cope or to help fulfill patient's wishes. Use this code if NOK expresses thanks to TR beyond the statement "thank you".

4A. Other _____

Use the "Other" code when you hear something that is a positive affective attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

5A. None

Choose this code when none of the above codes apply and there are no positive affective attitudes present.

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B. Negative: *Negative affective codes reflect the NOK having affective attitudes that are NOT in favor of tissue donation in some way.*

1B. NOK feels guilty

Use this code if NOK says s/he doesn't want to upset the family or feels upset or guilty in general about decision. Also use this code if families have a difficult time making the decision on their own or want the advice/input of other family members and/or friends. NOK needs to show some sort of hesitation or feeling of regret beyond just wanting to have an educated discussion about the topic with the rest of the family, friends, or others. NOK goes against his/her standing attitude towards donation in order to respect the opinion of others. He or she may be resentful about their decision, whether it is that they are uncomfortable making it without the input of others or that they feel bad about the decision itself (generally in the case where they are respecting the patient's wishes though they feel it's a good thing to do). The NOK also may not feel comfortable with the responsibility of making a decision about donation. Examples of this would be if the NOK said, "I can't make the decision myself", "I can't make the decision because I never discussed it with him/her (patient)"; or "I don't feel right making the decision alone." Scenarios of when this code might be used are: Example 1) NOK is for donation but is unsure what siblings/family members want to do; Example 2) NOK doesn't support donation but patient expressed wishes in favor of donation; Example 3) NOK recognizes the positive aspects of donation but doesn't know the patient or his/her wishes well enough to feel confident with his/her decision.

2B. "Ick" factor

The "ick" factor is a negative emotional reaction of disgust to the idea of tissue donation, in this case. Use this code if NOK responds to the request of tissue donation with disgust with a statement such as, "Ew!", "That's gross!", or says that anything regarding tissue donation makes him/her feel squeamish or uncomfortable.

3B. NOK feels that tissue donation is barbaric

Use this code when NOK use the term "barbaric" or use a similar adjective to describe tissue donation. NOK might say that tissue donation is eerie, inhuman, or heartless for which you would use this code.

4B. NOK feels that tissue donation is offensive

The NOK may tell the TR that s/he is offended to be receiving a call about tissue donation when his/her loved one just passed away. Use this code if the NOK specifically says that s/he is offended by not only the call/request, but by any part or process of tissue donation or by tissue donation itself.

5B. Request too difficult to understand at raw moment in life

This code should be used when says s/he feels too tired or overwhelmed with the request for tissues and s/he can't think about it right now.

6B. NOK does not want patient's body to be touched

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This code should be used when the NOK specifically says s/he does not want the patient's body touched by anyone on the donation team.

7B. NOK does not want patient's body to be cut on

Use this code if NOK refers to mutilation, disfigurement, the patient being cut on or cut into.

8B. NOK/family has been through enough already

Use this code when the NOK says that s/he or his/her family has "been through enough" with patient's death or medical illness.

9B. Patient has been through enough already

Use this code if NOK states that the patient has suffered through enough either through death or with medical illness.

10B. NOK wants to remember patient the way s/he was

Use this code when NOK says, "I don't want him to be any different than how I remember him" or "I want to remember him the way he was."

11B. Details of tissue donation not important

Use this code when NOK says s/he does not need to hear any further because s/he already knows about tissue donation or is not interested in knowing.

12B. Tissue donation conjures negative imagery

Use this code when NOK talks about tissue donation being too graphic or they are "imagining" something horrible happening to the patient's body, as an example. This code should be used when NOK describes a negative image that come to mind when they think about tissue donation.

13B. NOK feels that donating tissues is going too far

Use this code when NOK feels that donating the patient's tissues is too much to donate. A situation might be that the NOK donated the patient's organs and feels that donating the tissues is going too far.

14B. Other _____

Use the "Other" code when you hear something that is a negative affective attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

15B. None

Choose this code when none of the above codes apply and there are no negative affective attitudes present.

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2. NOK's behavior-based attitudes.

A. Positive: *Positive behavioral attitude codes are behaviors that are in the direction of donating tissues.*

1A. NOK is a registered donor

Use this code if NOK says, "I'm a donor" or somehow indicates that s/he is signed up on the donor registry and intends to one day donate.

2A. NOK supports patient's wishes

This code should be used when the NOK says that they have always supported patient's endeavors, wishes, etc. and want to follow the patient's wishes here as well.

3A. NOK had a discussion about donation with patient

Use this code if NOK says that s/he talked to patient about tissue donation or patient's donation wishes. This code can also be used if NOK says that the patient told NOK what s/he wanted to do regarding donation.

4A. NOK told patient tissue donation was a good thing to do

Use this code if NOK said s/he told patient at some point that s/he thought donation was a good thing to do. For example, "Before my daughter got her license she asked me about donating her organs and tissues and I told her I thought it was a worthy cause."

5A. NOK has discussed donation with family

This code should be used when NOK says that s/he has had conversations about donation with family members (ie. parents, siblings, cousins, grandparents, children, etc)

6A. NOK has discussed donation with friends

Use this code when NOK says that s/he has had conversations about donation with friends

7A. NOK has discussed donation with others

Use this code when NOK says that s/he has had conversations about donations with others (ie. co-workers, members at his/her church, acquaintances, etc.). This code may also be used if NOK doesn't specify who s/he spoke with, but just says that they've spoken to people in general.

8A. NOK has donated before

This code should be used when the NOK mentions any sort of previous experience donating, whether it's tissues or something else like blood, bone marrow, etc. An example might be that an NOK says, "I've donated blood before."

9A. NOK was/is involved with donation in some way (Specify:_____)

Use this code when NOK says s/he is involved with donation in some form. For example, the NOK might be a volunteer at organ donation marathons every year, may be involved with the hospital to promote donation, or may be a philanthropist for organ/tissue donation

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campaigns. Also use this code if NOK says s/he has a family member who was a recipient of donation.

10A. Other _____

Use the "Other" code when you hear something that is a positive behavioral attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

11A. None

Choose this code when none of the above codes apply and there are no positive behavioral attitudes present.

B. Negative: *Negative behavioral attitude codes are behaviors that are in the direction of refusing tissue donation.*

1B. NOK told patient tissue donation was NOT a good thing to do

Use this code when NOK says that she talked to patient and told her she didn't think tissue donation was a worthwhile cause. For example, "When my son got his license and told me he registered to be a donor, I told him I didn't like the idea."

2B. NOK is NOT a registered donor

Use this code when NOK specifically says that she is not a donor or does not intend to be.

3B. NOK does NOT support patient's wishes

Use this code when NOK demonstrates or says that s/he does not support patient's wishes. For example, after the TR may say that patient is on the registry, NOK might say, "It doesn't matter. I'm just not comfortable with it."

4B. NOK has discussed donation with family

This code should be used when NOK says that s/he has had conversations about NOT wanting to donate with family members (ie. parents, siblings, cousins, grandparents, children, etc)

5B. NOK has discussed donation with friends

Use this code when NOK says that s/he has had conversations with friends about NOT wanting to donate or being against donation

6B. NOK has discussed donation with others

Use this code when NOK says that s/he has had conversations with others (ie. co-workers, members at his/her church, acquaintances, etc.) about NOT wanting to donate or being against donation. This code may also be used if NOK doesn't specify who s/he spoke with, but just says that they've spoken to people in general.

7B. Other _____

Use the "Other" code when you hear something that is a negative behavioral attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

8B. None

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Choose this code when none of the above codes apply and there are no negative behavioral attitudes present.

3. NOK's cognitive-based attitudes.

A. Positive: *Positive cognitive attitude codes are cognitive-based beliefs, whether correct or incorrect, that support donating tissues.*

1A. NOK believes it's the right thing to do

Use this code when NOK expresses some sort of moral imperative to donate patient's tissues. NOK is confident about his/her decision and shows strong positive emotion towards donation. General statements about tissue donation that are positive overall/ or relate to tissue donation as a process, not what it does for other, would utilize this code. This code should be used when the NOK expresses an appreciation for tissue donation as an act. For example, this code would be used if the NOK says something such as, "it (tissue donation) is good," "more people should donate tissues," "I regret that I can't consent without knowing what they (patient) wanted." The NOK might say: "I think it's the right thing to do", "I think it's a good idea", "I think we should/will because...."

2A. It's better the tissue is used than unused

Use this code if NOK refers to tissues going to waste if not used or says something like, "why not if it can do some good." Also use this code when NOK says, "You can use whatever you can".

3A. Patient is just a body, not a person

This code should be used when NOK says that the patient is no longer a person, s/he is just a shell or body. The NOK acknowledges that the patient is no longer alive and may say this to justify why s/he is ok with donating patient's tissues.

4A. NOK believes tissue donation saves lives

NOK may be confusing tissues with organs in terms of their life-saving capacity. Nonetheless, use this code if NOK says that tissue donation saves people's lives.

5A. NOK believes tissue donation helps people

Use this code if NOK says anything about tissues helping others or the use(s) of donation. For example, s/he may say, "if it helps others....". This code may be used if NOK discusses how tissues may improve the health of others or do "some good". This code should be used when the NOK mentions the beneficiary of donation. The NOK has to specifically mention a person or persons such as saying, "I think this decision will help others in need" as opposed to just saying "I feel like I made a good decision about donation". Use this code when NOK expresses that tissue donation is useful: "There's a great need for it," "I'm happy to give this gift," "Take whatever is useful."

6A. Other _____

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Use the "Other" code when you hear something that is a positive cognitive attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

7A. None

Choose this code when none of the above codes apply and there are no positive cognitive attitudes present.

B. Negative: *Negative cognitive attitude codes are cognitive-based beliefs that support NOT wanting to donate tissues.*

1B. Donation will alter patient's appearance

Use this code when NOK says s/he thinks tissue donation will affect the patient's appearance or how the patient looks.

2B. There will be nothing left of patient

This code should be used when NOK says "there will be nothing left of patient to bury" or "they'll take so much that there won't be anything left of him." Basically, NOK is concerned that after the tissues are procured there will not be anything left over for any purpose, whether it be for burial, to touch, etc.

3B. NOK believes patient is still alive in some way

This code refers to when NOK makes a statement about the patient in the present tense or says something to show that s/he still thinks of patient as being alive. NOK might say, "I don't want him to suffer any more" alluding to the fact that patient is still alive and can feel the surgery being done to remove the tissues.

4B. NOK believes tissue donation will delay the funeral

Use this code when NOK says s/he doesn't want the funeral to be delayed or makes a statement about how s/he thinks tissue donation will delay the funeral.

5B. NOK believes tissue donation will affect the viewing

Use this code when NOK does not believe s/he can donate because donation will impact the viewing. For example, NOK might say, "I'm not sure [about tissue donation] because we want her to have a viewing" indicating that this false belief is affecting the NOK's decision to donate. This code can also be used when NOK says something specific like, "you can't take his hands because you'll be able to tell at the funeral."

6B. Patient's body will not be treated with respect

Use this code if NOK expresses concern about the staff not acting in a professional manner with patient's body, that s/he does not know what will happen behind closed doors once s/he agrees to donation, or questions/is concerned with how the patient's body is handled.

7B. NOK believes that patient's tissues are not suitable for donation

This code should be used when NOK makes statement about patient's suitability to donate or the viability of his/her tissues. NOK will usually explain why s/he believes the patient is not

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eligible for donation or why the TR would not be interested in taking the patient's tissues. NOK might say "his tissues won't do you any good" or "no one will be able to use them" or "I don't think you can use his tissues." NOK might explain that the patient had broken bones, s/he used glasses or that his/her eyes cannot be donated because they had cataract surgery or glaucoma, to name a few examples.

8B. NOK believes that tissue donation will cost him/her money

Use this code if NOK indicates that s/he thinks donation will cost the family money. NOK may say, "we can't afford to do this" or "the funeral home will charge more for this". Generally this code should be used for an NOK's misconception about the altruistic nature of tissue donation, that tissue donation is not a gift, that there is a financial commitment attached to donation.

9B. NOK believes that tissue donation is only possible with cremation

Use this code if NOK specifically mentions cremation. NOK may couch this thought with the fact that s/he is having a funeral or wants to have a viewing. NOK might say "well we're not having him cremated", something to indicate that s/he thinks donation is contingent upon having patient cremated.

10B. NOK thinks s/he has to go to the hospital to donate patient's tissues

This code should be used when NOK discusses going to hospital to fill out paperwork in order to donate. NOK might talk about his/her schedule and when they might be able to meet up with the TR to sign the paperwork before s/he is aware that consent takes place over the telephone.

11B. NOK believes that the patient will not be able to be buried

This code is specifically for when the NOK has a concern about the burial. NOK believes that it will be difficult to have a burial or that it will not be able to be done because of the way tissue donation is.

12B. Not enough medical attention will be provided to patient

Use this code when NOK makes a statement referring to the false belief that not everything will be done to save patient or the patient will not be saved if in an accident and is a donor. If this code is used, it is likely that NOK confused tissues with organs and the answer to Q9 should be coded as "Yes".

13B. Patient is too sick to donate/has too many medical conditions

This code is similar to code 7B above regarding suitability and may be coded in addition to 7B, but this code is more specific. Use this code when NOK specifically talks about the patient being too sick or has been through too much or has had too many medical conditions in the context of suitability of patient's tissues. NOK may mention that patient had cancer, was on chemotherapy, or had multiple heart surgeries and was diabetic.

14B. Rich people get organs/tissues faster

Use this code if NOK says anything about celebrities or wealthy people, people who have the financial means are more likely to receive and reap the benefits of the donated tissues. NOK might mention something they saw on TV, ie. Dick Cheney receiving a heart shortly after being

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placed on waiting list and thinking this happened because he's a famous politician. If this code is used, many times you can code "yes" for Q9 that the NOK confused tissues with organs as most of the media or false beliefs are rooted in information provided about organ donation.

15B. Patient's body parts will be taken

Use this code if NOK mentions body parts being taken from patient. NOK might use the term limbs, extremities, arms, or legs.

16B. Tissue donation does NOT save lives

Use this code if NOK feels that tissue donation only enhances lives or improves the quality of lives or specifically says that it does not save lives. NOK is concerned that donation will not be used in a life-saving capacity. NOK might compare to organs, saying that it doesn't help people the way organs do.

17B. Tissue donation industry is all profit-driven

This code should be used when NOK states that companies, pharmaceuticals or others will profit off of donated tissues and this makes NOK uneasy. NOK might make a more general comment about the tissue donation industry. The NOK needs to make a statement beyond just that want the tissues to be donated to non-profit companies or that they do not want it to go to for-profit companies. NOK needs to express more about what they think.

18B. Tissue donation industry is sinister and manipulative

This code should be used when NOK expresses distrust in donating tissue to those that receive the tissues. NOK may talk about people stealing body parts and selling them for profit or that companies are sneaky or not looking out for the best interest of the donors.

19B. Tissue donation is not possible because patient is dead

This code refers to when NOK says "but they're dead" or "I didn't know he could donate after he's already passed" demonstrating confusion about when tissue donation takes place. When this code is used, listen carefully to see if NOK demonstrates confusion between organs and tissues (in which case you would code Q9 as "Yes" to confusion of tissues with organs) as NOK may still be thinking about donation of organs and not tissues.

20B. Tissues will be wasted (i.e., 'thrown away')

This code should be used in two scenarios. One scenario is when the NOK thinks that the tissues will be thrown away if not donated – s/he might say "they'll be thrown away anyway, so why not?". The second scenario is when the NOK thinks that during procurement of tissues, some tissues will be kept and others will be thrown away, that not all of it will be donated and that concerns NOK.

21B. Patient is too old to be on registry/donate

Use this code when NOK mentions that the age of the patient would prohibit him/her from donating tissues. NOK may also say that their loved one was too old to be on the registry. Use this code whenever NOK refers to the patient being too old to donate.

22B. NOK will not be able to see patient again

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Use this code if NOK expresses concern about not being able to see the patient after donation takes place, whether because the body will be sent directly to the funeral home, to be cremated, or because the procurement team will keep NOK from seeing patient again. This code can also be used if NOK doesn't think s/he will be able to see the patient again due to his/her appearance after the procurement of tissues (ie. skin donation will make it difficult for NOK to see patient again).

23B. Patient will not feel the same

Use this code when NOK states that the patient will literally not feel the same as far as when s/he touches their loved one or holds his/her hand it won't be the same. NOK may state that other parts of the patient's body will not feel the same.

24B. Patient will not look the same

This code should be used when NOK is specifically concerned or states that their loved one will not look the same, will look different than before or anything that has to do with the patient's appearance being altered or different.

25B. Patient wanted to go out of the world the way he came into it (whole)

Use this code when NOK talks about patient's wishes as far as his/her body is concerned (being whole after death versus donating parts of body). NOK may state, "s/he wanted to go out of the world the way s/he came into it". NOK might say this generally or in the religious sense.

26B. NOK wants the patient to go out of the world the way he came into it (whole)

Use this code when NOK talks about how s/he wants the patient to leave the world the way s/he came into it (being whole after death versus donating parts of body). NOK may state, "I think Sam should go out of the world the way s/he came into it". NOK might say this generally or in the religious sense.

27B. It's against patient's religion

Use this code when NOK says that tissue donation is against patient's religion. NOK may explain that patient did not believe in this sort of thing, or "s/he was a Christian" "s/he was Jewish" and that "this is not something s/he would agree with."

28B. It's against NOK's religion

This code should be used when the NOK does not say that it was against patient's religion but states directly or indirectly that s/he does not agree with donation due to religious beliefs. For example, NOK might say, "The bible says this sort of thing isn't acceptable if you want to get into heaven."

29B. Eyes are the windows to the soul

This code specifically refers to the donation of the patient's eyes or corneas. The NOK will state a spiritual belief about the eyes such as that they are the windows to the soul.

30B. Patient needs all his/her parts to get into heaven

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This code is similar but slightly different than code 28B above "it's against NOK's religion". This code should be used only when NOK states that the patient needs all his/her parts to go to heaven. NOK does not need to make a statement about it being against NOK's or patient's religion in order for this code to be used. NOK may state that s/he doesn't not know if the patient will need his/her organs or tissues in the afterlife.

31B. NOK thinks the patient's tissues will not do any good

Use this code when NOK expresses his/her concern about the patient's tissues not doing any good. S/he might say, "I really don't think his tissues will help anybody". This code may be used in tandem with code 7B (suitability).

32B. Other _____

Use the "Other" code when you hear something that is a negative cognitive attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

33B. None

Choose this code when none of the above codes apply and there are no negative cognitive attitudes present.

4. NOK's OTHER Attitudes

These attitudes are categorized as "other" as they do not cleanly fit into any of the three cognitive components, affective, behavioral, nor cognitive.

1. NOK wants to spare other families the grief s/he is experiencing

Use this code when NOK states that they want to help someone else so that they don't have to go through what s/he is going through. NOK might say, "I don't wish this on anyone."

2. NOK feels that tissue donation is not necessary

Use this code when NOK says something to reflect that they feel that tissue donation is not an important endeavor, that it's a waste of time, or that it's not less important than organ donation. An example might be, "We already donated Jane's organs. I don't feel the need to donate more."

3. NOK is against patient having another surgical procedure

Use this code if the NOK says, "Another surgery is too much" or "I don't want him to go through another surgery." This code may come up after the TR says that the procurement process is similar to that of a surgery.

4. NOK does not want to prolong the consent process

Use this code if NOK says s/he expresses urgency to finish the process or get the body to the funeral home. Use this code also if the NOK says s/he just wants to get this over with so s/he can move on.

5. Other _____

Use the "Other" code when you hear something that is a negative cognitive attitude and does not fit into the above codes. Please summarize what code you think the statement should be.

6. None

Choose this code when none of the above codes apply and there are no negative cognitive attitudes present.

5. Counter-arguments.

Counter-arguments refer to **information that the TR provides** the NOK in order to dispel myths, false beliefs, or confusion about tissue donation or the tissue donation process. Please code for all counter-arguments that that the TR provides in the conversation that are specifically in response to any false beliefs, misconceptions or confusion that the NOK has or that the TR perceives the NOK to have based on comments, statements, or utterances s/he makes.

1. Prostheses will be put in place of bone to keep the body's shape

Use this code if the TR provides an explanation about prostheses being used after the tissues have been procured in order for the patient's body to maintain its shape. The TR may not use the term prostheses per se. Any statement that refers to how the body will keep its shape should be coded here.

2. Tissue donation can improve the health of others

Use this code if the TR explains that tissue donation helps others with medical conditions or improves others' lives. The TR may also say that tissues donated may enhance someone's quality of living. Examples include "it will help a child walk again", "it will help two individuals see again," "the valves can be donated to someone with defective heart valves so they can resume their normal way of living".

3. Tissue donation can save lives

This code should be used when the TR states that tissue donation can save lives. This code should be used when the TR specifically refers to how tissues "save lives".

4. Explanation of the possible gifts

Use this code when the TR provides an explanation of the different types of gifts or tissues that can be donated. The TR might say, "...and he could give the gift of sight with the donation of his corneas" or "bone can be donated and be used in pediatric patients with cancer or crushed into a powder-like substance to be used for dental implants."

5. Tissue donation is a way of honoring patient

This code should be used when the TR mentions how tissue donation honors the NOK's loved one, carries out his/her legacy, or honors the patient's wishes. This code can be used for any statement having the same meaning as these examples.

6. Patient can still donate with a medical history

Use this code when the TR counters the NOK's false belief that the patient is not a good candidate for donation due to his age, medical conditions, or health. Use this code when TR

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tries to explain to the NOK that these factors do not necessarily rule out a patient, or that there are other tissues that can still be used, for example, "he can still donate his skin".

7. Patient is on the registry

Use this code anytime the TR says that the patient or NOK's loved one is a registered donor or is on an online donor registry. The TR may say this in the beginning of the request conversation if s/he senses that the NOK might not be interested and/or to inform the NOK of the patient's wishes.

8. Tissues can have a longer life span than organs

Use this code when the TR states that tissues have a long lifespan, that they can be stored for years or just weeks (ie. corneas can be placed in a recipient in two weeks). This code should be used when the TR is comparing tissues to organs in order to show some of its benefits and far-reaching impact.

9. There's a variety of tissues that can be donated

Use this code when the TR explains that there are many different types of tissues that can be donated. This code should not be used if the TR is not prompted to emphasize this point (for example, do not use this code when the TR says at the beginning that the patient is eligible to donate skin, corneas, and bone).

10. It's not the eye, it's the cornea or the contact lens portion of the eye

This code should be used when the TR explains that the cornea is eligible for donation, not the whole eye or eyes. The TR might say this after the NOK says "his eyes were no good" or "I didn't realize he could donate his eyes." The TR essentially clarifies the type of gift that the patient can donate and attempts to decrease confusion.

11. Tissue donation is different than organ donation

Use this code when the TR says that tissue donation is different than organ donation or explains how it is different from organ donation. The NOK might make a statement about organ donation to prompt the TR to distinguish between the two. The TR might not explicitly state that the two are different, but might say "you would not get to meet the recipient of tissue donation because the tissues will be distributed to many more individuals" in which case you would use this code as the TR is making a distinction.

12. Tissue donation still possible after patient has died

Use this code when the TR states that tissue donation is a possibility after the patient has died. This code may be used in addition to the code "tissue donation is different than organ donation" if NOK has confusion between the two and thinks that tissue donation is like organ donation in which the patient still needs to be life supports in order to donate.

13. The tissues are procured in a similar way as a surgery

This code should be used when the TR explains the process of tissue donation by saying that it is a surgical procedure just like any type of surgery. The TR might state that the procedure for tissue donation is done professionally or collected very carefully with a scalpel and the

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incisions are sewn back together. The TR might also describe how the tissue procurement team does the procedure.

14. The patient will be treated with respect

This code should be used when the TR discusses how the patient will be treated with the utmost respect or in a dignified manner.

15. The paperwork is done over the phone

Use this code when the TR counters the NOK's false belief that donation takes place in person or at the hospital or does not realize that the consent process takes place over the phone. The TR will state that the paperwork is done over the phone and the NOK can be re-contacted to do the paperwork, or that the NOK does not have to leave home to do this.

16. Donation is possible whether having a funeral, viewing, or cremation

Use this code when the TR explains that the NOK can still have a funeral, viewing or cremation if s/he decides to donate tissues; that certain procedures or steps will be taken to ensure that these events will not be adversely affected. TR might be prompted to say this by the NOK expressing concern about the funeral, viewing or cremation.

17. Redirect NOK to clergymen

Use this code when the TR tell the NOK that s/he should speak with their clergymen or religious leader about when it is acceptable to donate patient's tissues. TR may say this in response to the NOK expressing uncertainty about donation due to the patient's or NOK's religious beliefs.

18. There is no cost associated with tissue donation

Use this code when TR dispels NOK's concern about there being a cost associated with tissue donation. The TR might say, "No, sir. There is no cost to you or your family to donate tissues" or "We take the responsibility of all the costs associated with donation."

19. Other _____

Use the "Other" code when you hear a counter-argument that does not reasonably fit into the above codes. Please summarize what code you think the counter-argument should be.

20. N/A

Use this code when there are either no counter-arguments or this question is not applicable to the case you are coding. An example of when "N/A" would be used is if the NOK says "no" to tissue donation and does not give the TR any opportunity to say anything.

6. Did the NOK have different attitudes after receiving information/counter-arguments?
This question is trying to see whether the NOK's attitudes changed from his/her initial attitudes after the TR provides the NOK with information or tries to dispel, modify, or reinforce some of the NOK's beliefs about tissue donation.

1. Yes

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Code "Yes" when the NOK's attitudes have clearly shifted, even if it is only one attitude that has changed. For example, the NOK may say, "I don't want to donate Tim's tissues because the family wants him to have a viewing." The TR may have provided the counter-argument of "A viewing is still possible with tissue donation and you will not even be able to see any scarring. Prior families have said they couldn't even tell their loved one's donated tissues." Code "Yes" if the NOK then acknowledges what TR said or says something like, "Well if you can't tell, then I'm ok with it."

2. No

Code "No" when the NOK's attitudes have not changed after TR has provided a counter-argument. An example might be that the NOK explains that she does not want to donate patient's tissues because it's against her religion. The TR might encourage the NOK to speak to her clergymen or might say that most religions are not opposed to donation. Code "No" if the NOK then sticks to her beliefs about being against donation due to religion.

7. Which counter-argument changed the NOK's attitudes?

This question has the same codes as question 4 and is asking which of the counter-arguments you coded in question 4 changed or affected the NOK's attitudes. There will likely be only one answer or code for this question, but if there are more please code for all that apply. Question 6 and question 7 correspond with questions 4 and 5.

1. Prostheses will be put in place of bone to keep the body's shape

Use this code if the TR provides an explanation about prostheses being used after the tissues have been procured in order for the patient's body to maintain its shape. The TR may not use the term prostheses per se. Any statement that refers to how the body will keep its shape should be coded here.

2. Tissue donation can improve the health of others

Use this code if the TR explains that tissue donation helps others with medical conditions or improves others' lives. The TR may also say that tissues donated may enhance someone's quality of living. Examples include "it will help a child walk again", "it will help two individuals see again," "the valves can be donated to someone with defective heart valves so they can resume their normal way of living".

3. Tissue donation can save lives

This code should be used when the TR states that tissue donation can save lives. This code should be used when the TR specifically refers to how tissues "save lives".

4. Explanation of the possible gifts

Use this code when the TR provides an explanation of the different types of gifts or tissues that can be donated. The TR might say, "...and he could give the gift of sight with the donation of his corneas" or "bone can be donated and be used in pediatric patients with cancer or crushed into a powder-like substance to be used for dental implants."

5. Tissue donation is a way of honoring patient

This code should be used when the TR mentions how tissue donation honors the NOK's loved one, carries out his/her legacy, or honors the patient's wishes. This code can be used for any statement having the same meaning as these examples.

6. Patient can still donate with a medical history

Use this code when the TR counters the NOK's false belief that the patient is not a good candidate for donation due to his age, medical conditions, or health. Use this code when TR tries to explain to the NOK that these factors do not necessarily rule out a patient, or that there are other tissues that can still be used, for example, "he can still donate his skin".

7. Patient is on the registry

Use this code anytime the TR says that the patient or NOK's loved one is a registered donor or is on an online donor registry. The TR may say this in the beginning of the request conversation if s/he senses that the NOK might not be interested and/or to inform the NOK of the patient's wishes.

8. Tissues can have a longer life span than organs

Use this code when the TR states that tissues have a long lifespan, that they can be stored for years or just weeks (ie. corneas can be placed in a recipient in two weeks). This code should be used when the TR is comparing tissues to organs in order to show some of its benefits and far-reaching impact.

9. There's a variety of tissues that can be donated

Use this code when the TR explains that there are many different types of tissues that can be donated. This code should not be used if the TR is not prompted to emphasize this point (for example, do not use this code when the TR says at the beginning that the patient is eligible to donate skin, corneas, and bone).

10. It's not the eye, it's the cornea or the contact lens portion of the eye

This code should be used when the TR explains that the cornea is eligible for donation, not the whole eye or eyes. The TR might say this after the NOK says "his eyes were no good" or "I didn't realize he could donate his eyes." The TR essentially clarifies the type of gift that the patient can donate and attempts to decrease confusion.

11. Tissue donation is different than organ donation

Use this code when the TR says that tissue donation is different than organ donation or explains how it is different from organ donation. The NOK might make a statement about organ donation to prompt the TR to distinguish between the two. The TR might not explicitly state that the two are different, but might say "you would not get to meet the recipient of tissue donation because the tissues will be distributed to many more individuals" in which case you would use this code as the TR is making a distinction.

12. Tissue donation still possible after patient has died

Use this code when the TR states that tissue donation is a possibility after the patient has died. This code may be used in addition to the code "tissue donation is different than organ

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donation” if NOK has confusion between the two and thinks that tissue donation is like organ donation in which the patient still needs to be life supports in order to donate.

13. The tissues are procured in a similar way as a surgery

This code should be used when the TR explains the process of tissue donation by saying that it is a surgical procedure just like any type of surgery. The TR might state that the procedure for tissue donation is done professionally or collected very carefully with a scalpel and the incisions are sewn back together. The TR might also describe how the tissue procurement team does the procedure.

14. The patient will be treated with respect

This code should be used when the TR discusses how the patient will be treated with the utmost respect or in a dignified manner.

15. The paperwork is done over the phone

Use this code when the TR counters the NOK's false belief that donation takes place in person or at the hospital or does not realize that the consent process takes place over the phone. The TR will state that the paperwork is done over the phone and the NOK can be re-contacted to do the paperwork, or that the NOK does not have to leave home to do this.

16. Donation is possible whether having a funeral, viewing, or cremation

Use this code when the TR explains that the NOK can still have a funeral, viewing or cremation if s/he decides to donate tissues; that certain procedures or steps will be taken to ensure that these events will not be adversely affected. TR might be prompted to say this by the NOK expressing concern about the funeral, viewing or cremation.

17. Redirect NOK to clergymen

Use this code when the TR tell the NOK that s/he should speak with their clergymen or religious leader about when it is acceptable to donate patient's tissues. TR may say this in response to the NOK expressing uncertainty about donation due to the patient's or NOK's religious beliefs.

18. There is no cost associated with tissue donation

Use this code when TR dispels NOK's concern about there being a cost associated with tissue donation. The TR might say, “No, sir. There is no cost to you or your family to donate tissues” or “We take the responsibility of all the costs associated with donation.”

19. Other _____

Use the “Other” code when you hear a counter-argument that does not reasonably fit into the above codes. Please summarize what code you think the counter-argument should be.

20. N/A

Use this code when there are either no counter-arguments or this question is not applicable to the case you are coding. An example of when “N/A” would be used is if the NOK says “no” to tissue donation and does not give the TR any opportunity to say anything.

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8. What attitudes changed?

In the space below, you should write in exactly which attitudes changed and specify whether it/they changed in the positive or negative direction. Include as much context as possible.

N/A

Code "N/A" if this question does not apply to the case you are coding or if you answered "No" to Q5 above.

9. Other external factors.

1. Funeral director said something

Use this code if NOK says that the funeral director or someone at the funeral home talked to them about tissue donation. Perhaps the funeral director said there would be added costs if donation was done, additional swelling to the body, more labor for the funeral home, or a delay in the funeral service. NOK may also say that the funeral director told him/her that tissue donation makes their job a lot harder, essentially dissuading the NOK from donating.

2. Hospital/Other experience

Use this code when the NOK had some experience beyond the death of the patient that caused him/her and/or the family to be upset. The NOK may have had a bad experience in the hospital with organ donation or with the doctors treating the patient, with a nursing home if the patient is elderly, with law enforcement if the case is a homicide/suicide, or the Medical Examiner's office if an autopsy was involved. Only use this code if NOK mentions one of these places.

3. Not able to cope/handle stress

Use this code when the NOK is clearly unable to get through the conversation without taking significant pauses or breaks or asks the TR to call him/her back because the request is too much to handle at the time. NOK may be overly emotional, possibly dramatic, or in denial that their loved one has passed away. Use this code when the NOK says something to indicate that s/he is at the stage of grief of denial or is not yet ready to deal with this request.

4. Never heard of tissue donation before

Use this code when NOK clearly demonstrates that s/he has never heard of tissue donation before. NOK might say, "I've never heard of it before" referring to tissue donation or ask, "What's that?" This code should only be used when NOK indicates that they have had no exposure to tissue donation whatsoever.

5. Logistics

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Use this code when NOK expresses concern over the logistics of tissue donation. An example includes transporting the patient's body to another location to do the procurement. The NOK may not want the body to be transported anywhere else or may feel that it will delay things. Along the same lines, the NOK may be concerned about time constraints or getting his/her affairs in order (ie. financials, funeral, burial service, notifying family members of death, etc.). There are a lot of events that take place and tasks to be done after the death of a loved one and this code should be used for any mention of such events.

6. Med/soc too long

The Med/Soc is the Medical/Social History which is paperwork that must be completed by the NOK with the TR before s/he is able to donate the patient's tissues. The Med/Soc usually takes about 30 minutes to do. Occasionally the TR will offer to call the NOK back to do the med/soc when s/he is more comfortable. Use this code if the NOK comments that the Med/Soc is long or expresses irritation over the fact that it is 30 minutes long.

7. Med/soc too personal

The Med/Soc includes questions about the patient's sexual partners, habits, activities, drugs and other risky behaviors which may seem too invasive or personal to NOK. TRs have to go through the Med/Soc with every NOK regardless of the patient's medical condition as it is required by the FDA to do so. A patient may have been bed-ridden for 5 years, but the TR will still ask if s/he has engaged in any sexual activity in the last several months. The same may be asked to an NOK of a 13 year old patient. Use this code if the NOK is offended by the questions or says it's too personal or invasive.

8. Other _____

Use the "Other" code when you hear something that is an external factor and does not fit into the above codes. Please summarize what code you think the statement should be.

9. N/A

Use this code when none of the codes are applicable or when no external factors are mentioned.

10. Did NOK make any reference to or comment about TV, Movies, or Media?

1. Yes, it was positive

Use this code if NOK talks about a TV show, movie, or something from the media that features tissue donation in a positive way. There may have been a spot on TV that showed how tissues helped someone to walk again, for example.

2. Yes, it was negative

Use this code if NOK talks about a TV show, movie, or something from the media that features tissue donation in a negative way. NOK may mention sinister or manipulate aspects of the tissue donation industry highlighted recently in a newspaper article, for example.

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3. Yes, but it was neither positive nor negative

Use this code if NOK simply references the fact that s/he heard about tissue donation through one of these mediums but doesn't attach any positive or negative value to it.

4. No

Use this code if the NOK made no references to any of these mediums during the request.

11. Did NOK confuse tissues with organs?

This question taps into spill-over attitudes and beliefs from organ donation that the NOK may bring to the request conversation about tissue donation, which may be positive or negative.

1. Yes

Code "Yes" if NOK did confuse tissues with organs. The NOK confused tissues with organs if s/he says, "All tissues are life-saving", "I know they didn't do everything possible to save my loved one since his donor card was signed." Code "Yes" if the NOK uses the term "organs" instead of "tissues" when s/he describes why s/he thinks or feels a certain way about tissue donation.

2. No

Code "No" if NOK did NOT confuse tissues with organs. This code should be chosen if the NOK somehow acknowledges what the TR says about tissue donation, for example s/he asks a question about the corneas or skin.

3. No basis to tell

Code "No basis to tell" if there was no basis to tell if NOK confused the two, for example the conversation may not have lasted long enough to determine if there was any confusion or nothing that the NOK said led you to believe that s/he did or did not understand there was a difference between organs and tissues.

12. If s/he confused tissues with organs, how did s/he associate it?

This question addresses the thoughts/beliefs that families bring to the request conversation about organ donation that spill-over to tissue donation. Only answer this question if you responded "Yes" to Q9 above.

1. NOK associated tissues with organs in a positive way

Use this code if NOK associated tissues with organs by something positive such as, saving lives or to say that it helps others.

2. NOK associated tissues with organs in a negative way

Use this code if NOK associated tissues with organs by something negative such as, "I was afraid that they weren't going to do everything possible to save my loved one since he had a donor card."

3. NOK associated tissues with organs in neither a positive nor negative way

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Use this code if NOK uses tissues and organs interchangeably but doesn't attach either a positive or negative stereotype, false belief, or thought to it.

4. N/A

Choose this code if you answered, "No" or "No basis to tell" to Q9 above as this question is not applicable.

Other/Notes/Comments

Use the space on the instrument to write any additional comments you have about the case either to give it some context, to share an insight you have, or highlight something interesting about the case.

Vita

Lindsey Alanna Kurland was born on March 11, 1984, in Riverdale, NY, and is an American citizen. She graduated from Coral Springs High School, Coral Springs, Florida in 2002. She received her Bachelor of Science in Psychology from Duke University, Durham, North Carolina in 2006. She received a Master of Science in Forensic Studies from Florida Gulf Coast University, Fort Myers, Florida in 2008. She worked as Graduate Research Assistant for Dr. Rick Zimmerman from 2009-2011, and for Dr. Laura A. Siminoff from 2011-2013, both in the Department of Social and Behavioral Health at Virginia Commonwealth University, School of Medicine.