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### In Their Own Words: The Reasons Why People Will (Not) Sign an Organ Donor Card

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## In Their Own Words: The Reasons Why People Will (Not) Sign an Organ Donor Card

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This multisite, qualitative study of 78 family-pair dyads provides rich data on the reasons people cite for (not) wanting to sign an organ donor card in the context of family conversations. In this study, dyads were videotaped as they discussed 8 questions pertaining to their views on organ donation, beginning with the most general opinions and progressing to more detailed questions. Analysis of the transcribed data revealed that the most common reasons for wanting to donate organs were based on religion or a desire to help other people in need. The most common reasons cited for not wanting to donate organs were mistrust (of doctors, hospitals, and the organ allocation system), a belief in a black market for organs in the United States, and deservingness issues (that one's organs would go to someone who brought on his or her own illness, or who could be a "bad person"). One of the most surprising findings is that religion is offered far more often as a rationale for wanting to help sick people through organ donation than it was for not wanting to donate organs. These findings both support and contradict past studies based on quantitative survey data. Implications for the construction of more effective future organ donor campaigns are discussed.

An estimated one third of the general population has signed an organ donor card, and actual consent rates by family members for the donation of organs from a deceased loved one hover at approximately 50%. This rate of consent does not come close to meeting the demand for organ transplants by the growing number of people who are added to transplant waiting lists. Currently, 86,000 people are on the

transplant waiting list; about 6,000 of them are expected to die this year because of the lack of transplantable organs (United Network for Organ Sharing, 2004).

A growing body of literature has outlined the primary reasons why people are unwilling to donate their own organs, and these reasons appear to be rather complex. Almost all of the available data come from quantitative survey data, including national Gallup polls (Gallup, 1996), large multisite studies (Morgan, 2003), and the usual college classroom surveys (Birkimer et al., 1994; Ford &

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Smith, 1991; Horton & Horton, 1990, 1991; Kopfman & Smith, 1996). These studies indicate that two reasons for an unwillingness to donate organs dominate: the fear that doctors will declare death prematurely to procure one's organs, and the belief that organ donation is against one's religion. Other reasons that are frequently cited include a lack of knowledge (Lange, 1992; Morgan & Miller, 2002b; Morgan, Miller, & Arasaratnam, 2003; Yancey, Coppo, & Kawanishi, 1997), perceived social norms against organ donation (Morgan, 2004; Morgan, Miller, & Arasaratnam, 2003), medical mistrust (Hall, Callender, Barber, Dunston, & Pinn-Wiggins, 1991; Lange, 1992; Sanner, 1994; Stevens, 1998; Youngner, 1992), fear of bodily mutilation (Lange, 1992; Sanner, 1994; Spigner et al., 1999; Stevens, 1998), and a lack of understanding of brain death (Radecki & Jaccard, 1999; Siminoff & Chillag, 1999). On the other hand, the cause of organ donation is supported by a high level of awareness (about 85%; Gallup, 1996) and generally highly favorable attitudes toward organ donation (Rubens, 1996; Yuen et al., 1998). These reasons have been thoroughly reviewed, including their exact statistical relationships with willingness to sign a donor card, in Morgan, Miller, and Arasaratnam (2003).

Adding to the complexity of individual decision making about signing an organ donor card is the prospect of revealing one's decision to family members. Discussion about the wish to donate organs is critical; without family consent, very few organ procurement organizations will proceed with processes involved with organ donation, even though a signed license or donor card is considered a legal document under the Uniform Donor Act. Only half of those with signed donor cards (or driver's licenses) have talked about their decision with family. Family discussions about organ donation appear to be predicted by a high level of knowledge about organ donation (presumably because people feel able to counterargue misconceptions raised by family members; Morgan, 2004) and a belief that their family members will respond positively to the idea of organ donation (Morgan, 2004; Morgan & Miller, 2002a).

Although survey data give us a solid understanding of general attitudes and knowledge toward donation, they lack the detail that we can gain from hearing people express specific concerns and the reasons for those concerns. Although other studies have focused on the theory-based predictors of whether people will talk to family members about organ donation, these studies reveal the bases for the attitudes conveyed. This study combines naturalistic conversation between family members (because family communication is a key behavior that is encouraged by organ donation campaigns) with prompts to help participants add depth to their discussions.

## METHOD

### Participants

Participants for this study represent a volunteer sample. Advertisements were placed in campus newspapers at a large northern state university and a midsize southern state university. The ads specified that participants must bring a close family member over the age of 18 with them and that they would be paid \$40 for their participation in a 90 min communication study. When participants called for an appointment they were further told they would be asked to discuss a health-related issue. Institutional review board approval for all research activities was obtained from both universities where the data were gathered.

Forty dyads from the northern university and 40 dyads from the southern university participated in this study. Because of a videotaping error, two dyads from the southern university location were not useable, yielding a total of 78 dyads.

The sample consisted of 33 partner-spousal dyads, 30 parent-child dyads, and 15 classified as other (sibling, step-parent) dyads. Of these, 57 dyads were White, 11 dyads were African American, 1 dyad consisted of 1 African American and 1 White, 1 dyad consisted of 1 African American and 1 Latino, 6 dyads consisted of family pairs of other ethnicities, and 2 dyads had one participant not reporting ethnicity. The age of participants ranged from 18 to 67 years old ( $M = 35$ ). Of the dyads, 45 were male-female dyads, 26 were female-female dyads, and 5 were male-male dyads (two dyads had one participant not reporting). Of those reporting education level, 1 had some high school, 28 had a high school diploma, 58 had some college, 32 had a college degree, 12 had some graduate school, and 22 had a postgraduate degree. Thirty-eight dyads consisted of individuals who had both signed organ donor cards, 13 where neither had signed cards, and 27 where one of the dyad had signed a card.

### Procedures

When participants arrived at the study they were asked to sign an informed consent form and asked to be seated in an interaction lab that resembled a living room (two sofas or one sofa and a comfortable chair, positioned perpendicular to each other). In addition, the lab was fitted with unobtrusive cameras and a two-way mirror. The researcher was not in the room with the participants except to provide initial instructions relating to the nature of the activity.

To enhance the normalcy of their interaction, participants were asked to spend 10 min discussing their past few days and their summer plans. When the initial conversation ended, participants were instructed to select the top note card from a small stack of cards and to discuss the question. When they finished that question they were asked to work

through the rest of the questions one by one. On average, the interactions lasted approximately 45 min.

### Materials

Participants were given eight index cards printed with questions about the respondents' views of organ donation. Each card was turned over one at a time and the question was discussed until the respondents felt that they had finished expressing their opinions. The questions discussed by the family dyads appear in the Appendix.

### Data

Data for this study consist of the conversations participants engaged in when answering the questions presented on the eight index cards. The conversations were videotaped with the informed consent of all participants and all videotapes were transcribed. The transcribed verbal data were entered into Ethnograph (assuming Ethnograph is software, pls. provide, company name, location, and version number) for coding and analysis. Videotapes were retained for subsequent coding and analyses unrelated to this study.

### Coding

Coding of the data was completed in layers. The first layer of coding consisted of entering a code that corresponded to each question. Subsequent layers of coding focused on specific themes or concepts that the literature on attitudes and knowledge toward organ donation suggested. However, this coding scheme remained open and flexible so that new categories arising out of the naturalistic conversations could be included. This resulted in a final coding scheme that identified the reasons people discussed for wanting/not wanting to be an organ donor (including those not identified in past research), sources of information for their attitudes toward donation, perceived family support, information seeking about family opinions about donation, knowledge of facts, and perceptions of public opinion about organ donation. In this article, we focus only on the reasons people cite for supporting a decision to donate or to not donate.

### Analysis

The analysis for this article focused primarily on the reasons people expressed for their attitudes about organ donation. Although specific questions were designed to get specific types of information, the quality of a natural conversation means that there is often considerable overlap between the responses to these questions. Ethnograph allows for the selection of a specific question and will display all conversations related to that question, or it will allow for the selection of a specific code word and generate sequences of conversation across all dyads related to that code word. In

addition to displaying the text of the conversation, it also will display the frequencies that any given code occurs. This analysis, then, provides the reasons supporting donation decisions and quotations to illustrate the specifics of the reasons given. Supporting quotations were selected for their representativeness.

## RESULTS

### Overview

We identified seven overarching factors that affected respondents' willingness to donate their own or others' organs either positively or negatively, as well as a few other reasons that did not seem to fit into a more general category. These factors are

- Religion/spirituality, including the belief that it is consistent with Christian doctrine to donate organs; concerns about precluding an afterlife existence if organs are donated; desire to maintain bodily integrity; and the belief that donors transcend death by living through organ recipients.
- Altruism, generally focusing on the belief that "if you can help someone, you should."
- Mistrust of the medical system, including fear that doctors will prematurely declare death to procure organs, fear of medical mistakes in the declaration of death, and the belief that the organ allocation system favors the rich or famous.
- Belief in a black market for organs, evidence for which seems to be drawn exclusively from the mass media.
- Issues related to the "deservingness" of potential recipients, including factors such as age (children or young parents vs. the elderly), immoral or criminal behavior on the part of the recipient, and whether the potential recipient was "responsible" for his/her own illness (e.g., through excessive alcohol consumption or smoking behaviors).
- Family opinions about organ donation, framed simply as whether or not family members would be upset by the prospect of donation or conversely, would be very supportive of donation.
- Visceral/noncognitive reasons, including believing that donation would be "gross," the belief that recipients acquire the psychological traits of their donors, the fear of still being able to feel pain associated with organ procurement even though the surgery occurs after death, distress over the idea of the violation of the dignity of one's dead body, and the belief that it would be "bad luck" to sign a donor card.
- Other reasons included the belief that "they wouldn't want my organs," that there was no rush to decide to become a donor, and not feeling knowledgeable

TABLE 1  
Factors Affecting the Decision to Donate One's Own or Others' Organs

<i>Reason for (Not) Donating</i>	<i>No. of Dyads Mentioning</i>	<i>No. of Occurrences</i>	<i>No. of Dyads Expressing This as Reason to NOT Donate</i>
Religion/spirituality			
General religious reasons/concerns	60	118	7
Desire to help others	54	106	0
Concerns about afterlife	46	69	5
Desire to maintain bodily integrity	37	63	11
Effect on funeral arrangements	19	26	5
Survival after death through donation	2	3	0
Mistrust of institutions (hospital personnel, allocation system)			
Mistrust of doctors/fear of mistakes/premature declaration of death	85	162	60
Mistrust of allocation system, including favoring the rich or those with celebrity status	37	63	26
Black market for organs	27	32	20
Deservingness issues	26	43	24
Family wishes for/against donation	16	22	3
Factual issues	24	36	0
(Mis)understanding of brain death	18	29	0
Expenses involved with donation	6	7	0
Visceral/noncognitive reasons	55	87	19
"Ick factor"/disgust	15	27	3
No words to describe reluctance to donate	15	29	14
Transmutation of recipient	12	16	0
Fear of pain involved with donation after death (illusion of lingering life)	9	11	2
"Jinx factor"/bad luck to sign card or discuss wishes	4	4	1
Other	31	74	2
"No reason why not"	14	37	0
Organ donation not natural	2	5	1
Violation of one's dignity after death	3	7	1
Too old/will not want one's organs	4	9	0
Plenty of time to decide/not dying soon	2	6	0
Lack knowledge about organ donation	4	7	0
Never been asked to be a donor	2	3	0

enough about donation. Also, a number of people simply could not put into words the reasons why they did not want to donate.

The factors with the greatest amount of impact on an unwillingness to donate organs are mistrust of medical personnel and institutions, including the organ allocation system, a belief that donated organs could be channeled through a black market, and deservingness issues, including concerns that one's "gift of life" could be given to an alcoholic, a criminal, or other "undesirable" person. As stated earlier, a significant number of people stated that they simply could not put into words why they did not want to donate (about 9% of the total number of respondents).

Interestingly, religious issues did not appear to be of great concern to participants in this study, even among those who are highly religious. Religion was most frequently cited to be a reason for donation, and the notion that a person's afterlife might be compromised was often actually

ridiculed. Along similar lines, the general desire to help people was by far the greatest factor affecting the decision to donate organs. Other people were somewhat less altruistic in their expression of support of organ donation, essentially adopting a more pragmatic "hey, why not? I won't be using them" line of reasoning. Each of the primary overarching factors affecting the decision to donate is described in more detail below, including examples from the transcripts of the interactions. First, factors associated with an unwillingness to donate organs are discussed. Reasons supporting the decision to donate are discussed in a subsequent section.

#### Medical Mistrust

By far, the reason most frequently given for not wanting to donate organs is a deep mistrust of the institutions (and their representatives) involved, or potentially involved, with the process of organ donation. Forty-seven percent of

the dyads ( $n=37$ ) reported that these concerns are strong enough that they are a reason for not donating. Several dimensions comprise medical mistrust: fear that doctors will declare death prematurely to procure organs, misgivings about equity in the organ allocation system, and a general fear of medical error made by doctors and hospitals.

Declaration of premature death is the most heavily cited of these three concerns. Simply put in a conversation by Person 1 in Dyad 11: “If I’m sick, they won’t try and save me. They’ll just take my organs” (Lines 145–147). This concern runs so deep that some people believe that the only way to avoid the danger posed by renegade doctors is to not sign a donor card or reveal a willingness to donate on any hospital forms.

#### Dyad 14

- Person 1: It’s just  
 Person 2: [They’re] wanting, you know, to grab his organs  
 Person 1: Yeah.  
 Person 2: like a vulture ... “get outta here, you SOB.”  
 Person 1: It’s easier to say “No.” It’s easier just to say “No, they’re my organs. See ya later.” It’s kind of an easy thing to  
 Person 2: Well, by saying I’m not an organ donor, you ... you eliminate the possibility of the situation ever arising.  
 Person 1: Exactly.  
 Person 2: If you said no, nobody’s gonna be asking for you to sign a form to, you know, to excavate the organs once you die. But if you are an organ donor, then, you know, right after you die, there’s gonna be somebody there saying “Okay. Now we need to go take out these organs.”

Just as disturbing, there are people who had once declared their intention to donate their organs who have decided to revoke their organ donor status because of “something they read.” One person calls upon the government to protect the public from doctors and hospitals who want to declare the death of patients prematurely to procure their organs.

#### Dyad 23

- Person 1: I took off my organ donation [on my license].  
 Person 2: Why?  
 Person 1: Because I don’t want ... I’m scared that they’re gonna treat me less ... they’re not gonna give me the kind of health care that I deserve if they see that I’m an organ donor. And I have actually read things about that.  
 ...

Person 1: [T]he government has to protect people’s rights. That’s where it comes in. Because if the medical field had anything to do, as a business, they would just simply take organs as they choose ’em.

Person 2: Oh, yeah. They’ll start gutting you up like a deer.

Person 1: Yeah.

...

Person 1: Have you ever read a law about organ donation?

Person 2: No.

Person 1: Exactly.

The organ allocation system was also discussed frequently. There appears to be a general suspicion that celebrities and the wealthy are able to pull strings to get the transplants they need. Doctors are also indicted because of the power respondents assume they have to procure organs for their “special cases.” One recent example involves Jessica Santillan, a young Mexican woman who died at Duke Medical Center after a second transplant that attempted to correct a tissue-type matching error in a first transplant operation. Person 1 notes, in a cynical tone, about how “amazing” it was that two sets of heart–lung combinations were located in an attempt to save Jessica’s life.

#### Dyad 1

Person 1: But they got her two sets, amazingly.

Person 2: Yeah, isn’t that something.

Person 1: So there had to, I think there had to be some kind of ...and that’s ... yeah, well that’s a whole other issue, but ...they probably pulled some strings to get her that second set.’ Cause they screwed up.

Person 2: You better believe it.

Person 1: So I mean, I think all rules are meant to be broken, personally. You know, [they] break ’em if they feel the need.

Not surprisingly, the previous conversation reflects closely general public discourse about the case in the print and television news media (Morgan et al., 2005). Although this case increased interest in the fairness of the organ allocation system, the public has often wondered why celebrities were able to get the organ transplants they needed when others on the transplant waiting list languished near death. In this study, 14 dyads cited recipients’ celebrity status as evidence that the allocation system is potentially corrupt. Although, as might be expected, respondents frequently mentioned baseball player (and heavy drinker) Mickey Mantle, other important public figures were featured in these conversations as well. For example, Pennsylvania Governor Casey’s heart–liver transplant happened almost

immediately after he was put on the waiting list, causing great controversy.

### Dyad 1

Person 1: Like, what ... remember that governor, Governor Casey? There was a big controversy, a Pennsylvania governor a few years ago, [you know that guy], that had a ... needed a heart transplant a few years ago and he got it pretty quick. And everybody was ... well not everybody ... a lot of people were saying, "Gee, this really didn't take him very long, did it? Is it because he was governor that got a response or was he just lucky?" And there were some ... yeah, this was in the paper. It was for quite some time, in fact, and you still see it every now and then referred to. And, uh, the issue was well, maybe just 'cause he's a...a public figure, he has an inside track

Person 2: Right.

Doctors making routine medical errors also caused respondents some concern. The Jessica Santillan case was sometimes given as a specific example of how medical errors in transplantation could kill someone, even though this error harmed the recipient rather than the donor. Of course, there is a certain overlap between the fear of the declaration of premature death and the fear of medical errors. Although most people say that they fear doctors will falsely declare death to get their organs, others frame the fear of premature death simply as a possible error. This, in turn, is often a result of the respondent not fully understanding the irreversible nature of brain death. Some respondents referred to people who had awakened after a lengthy coma as evidence that doctors would have been wrong in moving forward with the organ procurement process, indicating a lack of understanding of the distinction between a coma and brain death.

### Black Market for Organs

Arguably quite related to a mistrust of medical systems involved with organ procurement and transplantation is a pervasive belief in a black market for organs. The black market for organs is sometimes imagined to be run through medical personnel and/or institutions, and sometimes thought to be run by mafia-type organizations. Other respondents do not specify who, how, or where the black market operates, but insist that "anything can be bought, so why not organs?"

Perhaps this is American cynicism, fueled by our capitalistic culture, where anything is for sale; on the other hand, a few respondents cited news stories about rich Americans traveling abroad for transplants from freshly

executed Chinese prisoners, or less spectacularly, to poor countries like Indonesia, where people are willing to sell their kidneys to avoid their own or their children's death by starvation. These stories are unfortunately true and have been documented by the United Nations, which is currently trying to pass international laws to protect the poor from exploitation by rich foreigners needing transplants who are unwilling to suffer through long waiting periods (leading, perhaps, to death) at home. Although a black market for organs does indeed exist abroad, there is no credible evidence that there is a black market in the United States. The conditions under which organ donation can take place (living or nonliving) are highly exacting. Blood and tissue types have to be matched, and the period of time for which organs are viable is so short that transplant recipients have to be prepped for surgery as the procurement process is simultaneously taking place.

But how can the general public be expected to know all of this? It has long been noted that nature abhors a vacuum, and in the absence of information that might convince most people of the impossibility of a black market in the United States, our worst fears are given full reign. The exchange between the family dyad following is typical in that a source for information about the black market is given (albeit one that Person 2 admits is fictional) and this information is extrapolated from to justify one's belief that the black market exists in the United States. The final assertion that when people have enough money anything can be bought is echoed throughout a number of the dyads.

### Dyad 59

Person 2: That horror show, and uh, [I] read a book on it, but uh, not anything

Person 1: What was the book about?

Person 2: You didn't read that?

Person 1: No, uh-uh.

Person 2: People going into the hospital for minor surgery and things are ... there was a tissue match about whether if it matched and they had buyers for them and then conveniently the person would go into a coma and be found dead. And they would ship them off to this, it wasn't exactly a nursing home, but somewhere where they could take care of them. But what they were doing was harvesting organs. And sell them and the person would immediately die in a coma, but actually all their organs was gone. But no one found out before they died and then they'd bury them. But, you know, I don't know what all I've read, but that's one I have.

Person 1: Do you think it really happens that way?

Person 2: I guess if you have enough to buy it with.

Person 1: For real?

Person 2: Yes, it's against the law here, but a lot of things go on here. If you have the money and know-how, you can buy anything you want.

### Deservingness of Recipients

The final major reason why people report a reluctance to donate organs involves the deservingness of potential recipients. Respondents frequently stated, with some exasperation, that if a person brought on their own illness through behaviors that they knew would compromise their health, such a person should not receive a transplant when other "innocent" victims of disease are left to wait. For example, respondents were not interested in having their own donated lungs used to save the life of a smoker or their donated livers to save the life of an alcoholic.

#### Dyad 1

Person 2: But I wish you could almost pick who gets it, you know.  
 Person 1: Yeah.  
 Person 2: like not this big, drunk famous celebrity, who,  
 Person 1: well  
 Person 2: you know, like you see, like Larry Hagman, I just saw him on TV the other day

There are even specific images of "deserving" recipients that respondents seemed to have in mind. The young, parents of small children, and people who were born with a disease were the most frequently featured in discussions as being deserving of transplants.

#### Dyad 1

Person 2: I don't want my organs to be wasted.  
 Person 1: On? Some loser?  
 ...  
 Person 2: I mean, I wish I would have, or my family would have, a say in  
 Person 1: Well you have to have  
 Person 2: I think they might tell you. The, they might say like "Oh, well, you know, your, her lungs went to a 25-year-old cystic fibrosis patient and her whatever, eyes went to this blind  
 Person 1: Yeah  
 Person 2: father of three.

In addition to parents and people who became ill through no fault of their own, children (as opposed to the elderly) also appeared to be thought of as deserving recipients of a person's own organs.

#### Dyad 35

Person 2: I know, but I'm saying, ideally, I'd like to be able to be like "I'd like a 12-year-old to have my heart."

Person 1: "Red hair, six freckles."

Person 2: I don't want some old man who needs everything in his body to have everything out of mine.

Another version of the deservingness theme centered on the moral character of the potential recipient of one's donated organs. Criminals, abusers, and "bad people" were not thought to be worthy of saving.

#### Dyad 13

Person 2: What if it didn't go to as good a cause as you think it would?  
 Person 1: So you'd feel bad about, um, your heart being inside of ... of a felon of some sort.  
 Person 2: Yeah. So, for instance, if you didn't donate your heart, if that person didn't get a heart, then they wouldn't have survived and they wouldn't have ... I don't know.

It should be noted that there were a number of people in this study who complained that prisoners had the same rights as others to receive transplants. The public seems to want to impose criteria that only upstanding citizens receive scarce resources like organ transplants.

In addition, there is a certain amount of moral or spiritual responsibility that some people seem to feel about the type of person saved with their own organs, as seen in the previous excerpt. One person even considered vengeance in the afterlife if her heart went to someone who beat his children:

#### Dyad 37

Person 1: And then, it's kinda, like, who are my organs gonna go to? I hope it doesn't go to somebody who's real mean and stuff. Someone who like, beats their kids. "I want my heart back." I'll come back from the grave and get my heart back. "Yo, meany. I want back my heart."

Some, like Person 2 of Dyad 43, were able to successfully counter this argument with a friend who thought it would be "bad karma" to have one's organs be placed into a "bad" person:

Person 2: When I was ... one time ... there was this girl that I became friends with ... . She hated organ donation and I said "Why?" and she said "Maybe they will let a criminal or someone who had really bad karma and their organ would be the flesh of someone that was bad and would you want to have that in your body?" and I said that act of giving your organ would give them absolution. ... She said, "I never thought of that."



The idea that the characteristics of a donor and a recipient would somehow be passed from one to another was not unusual. No one cited transmutation as a reason for not wanting to donate organs, but statements affirming belief in this phenomenon were made in 12 of the family dyads.

Figuring prominently in conversations between family dyads were reasons for wanting to donate organs. These included religious/spiritual reasons, a desire to help people in need, and a reason that can only be termed, “why not?”

### Religious/Spiritual Reasons

Contrary to many findings from quantitative studies of attitudes and beliefs about organ donation, respondents in this study frequently cited Christian beliefs as supporting organ donation. In fact, respondents who declared themselves to be strongly religious consistently stated that they could see no contradiction between Biblical scripture and organ donation. In fact, some respondents often mocked the idea that God would disapprove of organ donation or that their after-life would be somehow compromised if they consented to organ donation.

#### Dyad 14

Person 2: Your soul is eternal and, you know, you're in heaven and in heaven, you'll get a new body and this body isn't important anymore. It rots. So why not?

Person 1: You're not gonna be up there . . . . People aren't gonna frown upon you when you're in heaven, saying

Person 2: That's right.

Person 1: “Oh, you're the guy without kidneys.”

Person 2: Yeah, St. Peter is working through his list. “Oh, come on in. Whoa! You're missing a kidney. Sorry.”

Respondents who stated that they did not want to donate organs for religious reasons took one of two stances: Whereas a few said that there was no Biblical scripture that they knew of that actually supported organ donation, others simply said that “no one really knows” if a person needs their organs in the afterlife, and it would be best to be “on the safe side.” One respondent from Dyad 69 admitted that he was “picking and choosing” which scriptures to believe even while invoking the religious prohibition against the mutilation of the body. His astute daughter asked, “Oh, you have a tattoo, but you won't donate your organs?” In the end, he agreed to try to remain open-minded about the prospect of organ donation.

This last case is especially interesting because it may help to explicate the true nature of many (but certainly not all) so-called religious objections to organ donation. It may be possible that “religious objections” is a cover story for a general feeling of discomfort or uncertainty about organ

donation. Such a strategy would be especially convenient because it is unlikely that many people would argue with the person invoking religious objections. Supporting this logic are the handful of people who expressed uncertainty about what religious scripture or their religious leader had to say about organ donation but who made specific plans to actually ask their priest, minister, or rabbi about the issue. Such people genuinely questioned whether their religions supported organ donation and planned to actively seek out the answer. In other words, the importance of their religious conviction became a starting point for inquiry, not a way of suppressing further discussions about organ donation.

However, there were a significant number of people who expressed a desire to maintain bodily integrity, less as a product of their religious beliefs than a need to simply keep the body whole and unutilized. Such a desire may hark back to ancient taboos against mutilating (or even handling) a dead body that transcends any specific religion.

#### Dyad 35

Person 2: Do you want to be an organ donor? On my driving license, there is a note that I am an organ donor.

Person 1: Mmm . . . no. I don't know. I don't want to be an organ donor.

Person 2: Why?

Person 1: Because it is the same way why I am not letting our daughter pierce [her] ears. Because the body must be complete.

By no means was this a major reason for not wanting to donate organs. Of the 78 dyads, only 11 contained at least one person who expressed serious enough concerns that would keep them from donating their own organs.

### Desire to Help Others

The simple altruistic desire to help others was the most frequently cited motivation to donate organs.

#### Dyad 16

Person 2: I don't think there's anything better that you can do in your life, than giving organs to . . . to some deserving person, someone whose life may be very important to his or her family.

Person 1: Okay, so you've . . .

Person 2: There is nothing more fulfilling than that.

Interestingly, all but one of the respondents imagined a single recipient of their organs if they were able to donate. In reality, a single donor can save seven lives and improve the lives of 50 or more recipients. On the other hand, respondents who made statements like, “they'll cut you up like

a buffalo” may be all too aware of how useful a single donor can be—and the horror of having one’s body so thoroughly violated may ultimately be insurmountable, even to save the lives of others. However, a number of respondents commonly stated that any religious or bodily integrity concerns were more than outweighed by the imperative to help fellow human beings in need.

#### Dyad 64

Person 1: Living with my grandmother and being raised by her and [her] thing was that when you die everything is supposed to be buried with you. [But] it’s not taking a piece of you; it’s leaving a good piece of you because it’s helping someone else who may die too. Why two people have to die if you can help that one live? And that person may become something better than we need on this earth anyway.

...

Person 2: And I obviously feel that it’s good to be an organ donor. I think [my family] feels the same way as I do. Even leaving a piece of you behind to carry on and help someone else as a way of helping people. That’s where I think they’d be at.

Some people were motivated to help others because “if my son or daughter needed an organ, I would want others to donate.” Imagining the anguish of another family was clearly a motivating factor in wanting to donate organs.

#### “Why Not?”

There were a significant number of people who, rather than expressing an explicit desire to help others, took the approach that organs might as well be used for transplants because “they weren’t going to be using them any more.”

#### Dyad 58

Person 1: You gotta get a will together so you can tell everybody whether to donate your organs. And like I said, why would you not? You’d have to be a moron to want to hold onto the organs of a dead person.

Similarly, some people thought that it would be “wasteful” to bury perfectly good organs if they could be used by others. Person 1 of Dyad 14 said simply, “You know? I’d rather not go to waste if someone could use it.” This response is a rather pragmatic form of altruism. Rather than being motivated by high-minded ideals about helping humanity, this group of people adopt a “waste not, want not” mentality that nonetheless leads them to the same imperative to donate organs if the opportunity arises.

## DISCUSSION

This study has a couple of key limitations. First and foremost, these family members clearly spend more time discussing the issue of organ donation and in much greater depth than would be expected under normal circumstances. Virtually everyone in this study described other family conversations about organ donation as being very brief (if they happened at all). Many of the reasons for wanting to donate or not donate were elicited as a function of answering the specific questions that were inherent in the study protocol. However, because people rarely engage in family discussions about donation and because such conversations happen at moments that are not predictable, there is simply no way to capture unrehearsed or unplanned conversations about donation except in a laboratory environment.

Second, although the interaction laboratory was designed to look and feel like a living room to the greatest extent possible, participants knew that their discussions were being videotaped because they had to sign consent forms for the taping. This may have led to a certain degree of self-consciousness and may have even contributed to a positive bias toward the topic of organ donation. Although most of the reasons cited were negative in content, it is not known whether participants would have been even more negative in their private discussions. Future research should include measures of social desirability so the degree of positive bias in these discussions can be assessed.

Nonetheless, the findings from this study are important for communication practitioners for a number of reasons. First, the factors cited in the course of family conversations for each person’s willingness to donate organs frequently mirror (and, in fact, magnify) findings from quantitative studies. Medical mistrust and a belief in a black market for organs have long been noted as real barriers to the willingness to donate organs. Unfortunately, few researchers have offered insight about where these ideas have come from or how they might be countered. This is not surprising because survey data rarely provide enough rich detail to create a blueprint for messages to counter these misconceptions. The factors identified here as key barriers to donation must be singled out for special attention in future organ donation campaigns; it is simply not enough to discuss the overwhelming need for transplants to save lives.

Second, the findings from this study are important because they just as often cast serious doubt on other findings from previous studies. In direct contradiction to a number of traditional survey-based studies, participants in this in-depth qualitative study were far more likely to cite religious and spiritual reasons to support a willingness to donate. However, it should be said that although quantitative studies have often reported that religiosity is negatively associated with a willingness to donate, the effect sizes of the associations have always been weak. Morgan, (2004) speculated that it is the conservatism of religious belief,

rather than religiosity itself, that would be a better predictor of an unwillingness to donate.

Public education must focus on the process involved with donation—like the decoupling of medical teams devoted to emergency and trauma care from those involved with transplant surgery. Similarly, a better public understanding of the nature of brain death would be very helpful in the promotion of organ donation. There seems to be considerable confusion about the difference between *coma* and *brain death*.” Brain death, is in fact, “real” death, and a dead person can be mechanically maintained only for a very short time for the purposes of organ donation. Mechanical maintenance of a dead person is very different from the life support received by patients in a coma or a persistent vegetative state, but this does not seem to be understood by the public. The fear that medical staff will “pull the plug” to get a person’s organs is quite probably the most prevalent fear among the public.

One has to wonder where in the world the public gets fantastic notions about renegade surgeons who hover (in the words of our participants) like “vultures” and then “gut” their patients “like deer.” Or that back-alley murders and subsequent organ thefts are even medically possible, given the delicate nature of transplant procedures and the necessity for careful tissue-type matching? It may be possible that a fear of the unknown causes people to imagine the worst possible scenario. However, there is an easier answer: the media have long been exploiting our deepest fears about organ donation for entertainment value. Television series such as *Law and Order*, *ER*, and *X-Files* (and more recently, the hit show *Grey’s Anatomy*); daytime serials like *One Life to Live*; and countless movies, including *Dirty Pretty Things*, *Blood Work*, and *Return to Me*, have all presented patently false information about organ donation. Studies of the media are desperately needed to fully explicate the misinformation being consumed by the public so that organ procurement organizations can more specifically target the deepest (and most unfounded) fears.

Future qualitative studies of organ donation should explore further the nature of the deep ambivalence of the public toward organ donation. For example, our study revealed that overwhelmingly, people cited the amazing potential of organ donation to help people who are suffering from otherwise terminal illnesses. However, these same people went on to voice serious misgivings about organ donation, especially about institutions and individuals involved with the process of organ donation. As Person 2 in Dyad 78 said, “If someone would prove to me that just ‘cause you’re an organ donor and you were dying in a car accident . . . they would save you anyway.”

Easing these fears and fundamental ambivalence will be no easy task, and will certainly not be accomplished by sporadic campaigns of 30-sec public service announcements that simply encourage people to donate. Specific information about the safeguards built into the system

to protect potential donors and to ensure the equitable distribution of organs to deserving recipients must be disseminated, and misinformation about organ donation promoted by entertainment media must be persistently and aggressively fought. There is much at stake: because of fears fueled by a lack of accurate public knowledge, thousands of people die every year while waiting for life-saving transplants.

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## APPENDIX

### Questions Discussed in Family Pair Dyads

1. Please discuss whether you are organ donors or whether either of you would you consider becoming an organ donor—and the reasons behind your decision.
2. What have you heard about organ donation on television? What have you read about organ donation?
3. Do you have any religious/moral objections to organ donation? What are they?
4. Is there anything that worries you about organ donation? Any fears?
5. How do you think your other family members feel about organ donation?
6. How would you feel if the other person here with you today disagreed with your decision about being an organ donor? Could you each be supportive of the other person's decision?
7. In your perception, what's the family's role in your decision to become an organ donor? Do you feel that you need to tell your family if you decide to become an organ donor?
8. Have either/any of you talked about organ donation with any other family members? Who? What was the conversation like?