

Family discussions about organ donation: how the media influences opinions about donation decisions

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Abstract: In this study, 78 family pair dyads (spouses, parent–child pairs, or siblings) were brought into an interaction laboratory set up like a living room. After being briefed on the study, family members discussed a series of eight questions about their thoughts and opinions about organ donation. Thematic analysis of the thousands of pages of transcripts revealed that family members believe that they receive important information about organ donation through the media. Unfortunately, the most influential information came from sensationalistic, negative media portrayals. The myths that seem to be the most actively referenced by the media include premature declaration of death, the transference of personality traits from donor to recipient, a US black market for organs, corruption in the medical community, and corruption in the organ allocation system (which allows celebrities to get transplants first). Although these are not the only myths that the generally public holds to be true, the media is a powerful source of support for these particular myths. Therefore, such myths must be countered effectively if greater consent for organ donation is to be attained.

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Americans are highly aware of the acute need for organs for transplant and generally hold very favorable attitudes toward organ donation (1) even while the rate of donation has increased only slightly over the last 10 yr (see <http://www.unos.org> for statistics). Because the need for organs greatly outstrips the supply of donated organs (and because this gap grows every year), organ procurement professionals devote considerable efforts toward promoting organ donation. Unfortunately, they are often mystified as to why (with few exceptions) sustained campaigns and community outreach events have failed to translate into corresponding increases in the willingness to donate.

Moreover, the organ procurement community in the USA has strongly encouraged families to engage in discussions about organ donation. These efforts appear to have met with limited success because less than half of those people who have

signed a donor card have discussed their wishes with their families (2). An interesting recent finding is that an equal proportion of non-donors also appear to have discussed organ donation with family (3). As we have long assumed that talking to family would have a *positive* impact on organ donation, why would family discussions not yield a greater rate of signed donor cards or drivers licenses?

The study described here uncovered findings that were a by-product of the study's original intention. We began this investigation as a way to examine how real families engage in discussions about organ donation. What we found, however, was a pattern of conversation that referred to the media as a significant source of information, and more troubling, as a source of evidence that justifies an unwillingness to donate their own (or others') organs.

Although scholars like Maloney and Walker (4) document a generally favorable shift in coverage from the early years of organ transplantation where Frankenstein and vampire imagery comprised most of the framing, media treatment of organ donation seems to have regressed substantially in the 10-yr gap since Maloney and Walker's study (the latest coverage analyzed was during the first half of 1995). Their study charted fluctuations in media framing of organ donation from Frankenstein-like dissection of the human body by surgeons portrayed as vultures or vampires in the earliest years of media coverage to a recipient- or donor-centered perspective in the mid-1990s.

Maloney and Walker's research, however, was conducted in Australia and thus may have limited applicability to current media portrayals in the USA. Although most people who favor organ donation are likely to dismiss negative media treatments as 'just TV' or 'only Hollywood,' this does not necessarily translate into a negligible effect on the general population, which may have more ambivalent feelings about donation. In fact, Maloney and Walker's qualitative study of discussions about organ donation (5) did generally reflect the negative tenor of media coverage of organ donation. Similarly, some authors have expressed concern that negative, sensationalistic media coverage would impact interpersonal discussions about organ donation which would ultimately result in a lower consent for donation (6). In light of this limited prior research, the current manuscript was guided by the following research question:

RQ1: How does information about organ donation presented in the media manifest in family conversations about organ donation?

Methods

Participants

After IRB approval was secured, a total of 80 family-pair dyads participated in this study, half in a rural northeastern location (central Pennsylvania), and half in an urban southern location (Charlotte, NC). Consent rates for donation in each of these regions are comparable: 50% in eastern and central Pennsylvania and 52% in the Charlotte area.

Family dyads were recruited using advertisements in campus and community newspapers. Advertisements recruited participants for a study of family communication about health issues.

Dyads could consist of any potential 'next-of-kin' relationships: spouses, parent-child, or siblings. Individuals were paid \$40 for their participation in the study, which lasted a total of about 1 h. Because of a videotaping error, only 78 of the 80 dyads yielded data that could be transcribed.

Spousal dyads were the most common ($n = 33$), followed by parent-child pairs ($n = 30$), and other relationships (siblings or step-parents, $n = 15$). Most of the dyads were Caucasian ($n = 57$), though there were also African American ($n = 11$) and dyads of a variety of other ethnicities, including mixed race/ethnicity pairs ($n = 10$). Average age of the participants was 35.

Procedures

After completing surveys about their donor status and attitudes relevant to donation, participants sat in a living room-type setting with two chairs or sofas and a coffee table. All participants signed a consent form to be videotaped; cameras were positioned so as to be unobtrusive or virtually invisible. Participants then spent 10 min relaxing and talking about upcoming vacation plans. When participants felt fully relaxed, they picked up a set of eight index cards printed with questions beginning with the most general ('Are you a donor? Why or why not?') and finishing with the most in-depth ('How do you think your family members feel about organ donation?'). One by one, the cards were turned over so each question could be read. The interactions lasted an average of 45 min, with some questions provoking more discussion than others.

Materials

The eight questions that participants discussed appear in Appendix A. These questions were developed based on the Organ Donation Model (7) which is grounded in the Theory of Reasoned Action (8), and the Theory of Motivated Information Management (9). The Organ Donation Model specifies a number of variables that impact the willingness to donate and to talk to family members about donation, including one's own personal attitudes toward donation, the attitudes of family members and other important people, and cultural and spiritual values. The Theory of Motivated Information Management specifies that people will talk to family members (in this case, about organ donation) when they feel that family members can help them make a better decision. It should be noted that only certain questions provoked

responses that are relevant for the purposes of this manuscript.

Coding

After fully transcribing all interactions, the text was downloaded into a qualitative analysis software package called Ethnograph. Coding then proceeded in layers: first, text was coded for each question; second, the text was then coded for themes that emerged in the interactions. The coding scheme that emerged identified the reasons people discussed for wanting/not wanting to be an organ donor, sources of information for their attitudes, recall of content of media coverage of organ donation, perceived family support, information seeking, knowledge of facts, and perceptions of public opinion about organ donation.

Results

There were several questions that elicited discussions about organ donation featuring information participants gleaned from the mass media ('Are you a donor? Why or why not?', 'What have you heard about organ donation?', 'Is there anything that worries you about organ donation?'). Negative opinions about organ donation were almost always justified with information, stories, or images from the mass media, while positive opinions about organ donation were attributed to personal values and beliefs and only occasionally supported by stories about donors or recipients that participants heard or read in the mass media.

Discussions that referenced the media fall into two categories: (i) straightforward mentions of information that came from the mass media, including recitations of plots or content of show episodes; (ii) assertions of the 'truth' about organ donation based on the mass media.

Sources of information about organ donation

Specific television shows cited as sources. Law and Order, ER, The Learning Channel (TLC) and the Discovery Channel, Jag, Touched by an Angel, Charmed, Dateline, USA Today, Oprah, and Good Morning America were all specifically mentioned. In addition, some people mentioned that they had seen or heard something about organ donation on daytime serials ('soap operas'). Unfortunately, even accurate coverage of issues related to organ donation (usually featured on educational programs on TLC or the Discovery Channel) could have unintended effects by priming people to think

about other issues related to organ donation that concerns them.

Dyad 38

Person 2: You know that medical show on TV, last year, I wanna say on the Discover Channel or something, but I'm not even sure what channel it was on. But it was a pediatric heart ward. And these children were, basically, waiting for heart transplants and, you know, you didn't know at the end of the show which kids were gonna live and which ones were gonna die. And it was just gut-wrenching to watch that. I had...I didn't do well with that. I mean, you know, watching little kids die, you think about a 40 year-old dying because he drank himself or, you know, had some random kidney disease or something and well, like, they kinda got to live, but when you're looking at a five-year-old with a heart condition or something like that, that's pretty gut-wrenching. So...

Person 1: Mmmhmm.

Movies. Many movies were referred in broad generalities or as 'that movie where' something dreadful happened involving organ donation.

Movies aired 'on the Lifetime channel' were also cited. Specific movies mentioned included 'Return to Me,' 'Coma,' 'The Hand,' 'John Q,' 'Urban Myths,' 'Monty Python,' and 'Steel Magnolias.' While not every movie featuring plots (or subplots) pertaining to organ donation is negative, the vast majority blatantly plays on myths and misconceptions about organ donation. 'Return to Me,' a heart-warming movie starring Minnie Driver and David Duchovny nonetheless plays on the idea that recipients somehow acquire the traits of their donors or that there exists some kind of spiritual tie between donor and recipient. Although many real-life recipients and donors do claim this type of connection, this notion is a double-edged sword. In fact, many participants in this study cited serious misgivings about donating their organs because they were afraid of saving the life of a 'bad' person, thus making them spiritually responsible for this person's survival (SE Morgan, TR Harrison, SD Long, WA Afifi, MS Stephenson, T Reichert, unpublished data).

Myths about organ donation

Some participants asserted the truth of various myths about organ donation based on what they had seen or heard in the mass media. Sometimes

specific sources were cited, but often information was attributed to 'television' generally. Unfortunately, even though the content and the show itself were long forgotten, the influence of these shows on participants' general sense of cynicism and suspicion about organ donation remained.

Dyad 9

Person 1: Yeah, I have seen that on [...] shows.

Person 2: I mean, that's shows, but there's all those situations.

Person 1: Well, that's...yeah. I mean, a lot of those shows are...you can take half of that situation and make it real.

Person 2: You know, the world's so big, I'm sure that has happened.

In many cases, however, participants in this study were very explicit about the fears that were supported by the media. Specific myths include the premature declaration of death, belief in a black market for organs, corruption among doctors, corruption in the organ allocation system, and the transference of donor traits to recipients.

Donors 'not really dead'. It is probably no coincidence that participants frequently mentioned entertainment programming or movies that featured plots involving the procurement of organs from a patient who was not yet dead. Survey-based research has long shown that concern about the premature declaration of death is among the deepest and most strongly held fear about organ donation among the general public. The following example illustrates how the media perpetuates this myth.

Dyad 20

2: And then, like, there's always, like, that 'Law and Order.' Do you remember that 'Law and Order?' Did you see that?

1: Uhhuh. (No.)

2: That show where, um...there was a show about that, about this, um, doctor who was being put up for trial because the was, um...they found mistakes in his data or whatever, that showed that he, like took this person's organs before, like they were, like, fully, like,

1: Before the person was dead?

2: [before the person] was dead.

1: He was, like, almost dead, I guess, but he wasn't completely dead. So, ugh

2: [So, he] might have survived?

1: Yeah.

2: Ugh.

1: So then the guy got convicted? The

doctor did?

2: Mmmhmm.

...

2: [Well] that was the only thing I heard. Just that one about, um,

1: [So] it was on 'Law and Order.'

2: [on 'Law and Order.'] Yeah.

1: Which might or might not be true.

2: I don't think it's true. Those aren't true, are they? I don't think they're true.

1: You know, they base some of their stories on things they get out of the newspaper, I mean, things that really happen.

2: Yeah.

1: And I don't know if that particular one or I don't know if all of 'em, but you know, some of their stories are based on real events. Uh, and you know they make 'em seem like real life.

2: Yeah, they do.

Black markets for human organs. The belief in a black market for transplants is widespread among Americans, as demonstrated by multiple studies (1, 7, 10–14). It appears that this is not mere cynicism, as multiple episodes of Law & Order (which opens with the tagline, 'Stories ripped from the headlines') have featured black markets for organs. After the credits roll at the end of the episodes, brief notes state that the stories have been fictionalized. Thus, it is no longer a surprise that Americans think that black markets for organ transplants are a dark fact of life. Participants in our study not only cited the show as the source of their information, but in some cases (as in the one above), also recited the plot of a particular episode.

Dyad 21

Person 1: And, uh...so, no, I'm not really...of course, I don't think anyone would intentionally steal an organ. I'm thinking of a scary movie where they take the kidney,

Person 2: Oh, God.

Person 1: that kind of thing doesn't

Person 2: [And] sell it on the black market?

Person 1: And sell it on the black market.

Person 2: [It happens.]

Person 1: Alright. Do you think it happens?

Person 2: Oh, yeah.

Person 1: Do you really?

Person 2: Yeah.

Person 1: They'd, like, if you were in the hospital having surgery and they're intentionally take your kidney while they're in there fixing your heart?

Person 2: Well, I don't know if they do that. It'd have to be really

Person 1: Yeah, that'd

Person 2: [messed] up.

Print media also contribute to the promotion of myths about organ donation, even though study participants clearly understood that they were reading fiction.

Dyad 57

Person 2: That horror show, and uh, 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 were 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. But, I would hear it on television. I don't recall where. I remember hearing about it two times.

Celebrities get transplants first. It is easy to understand why many people perceive that celebrity status plays a role in whether people receive life-saving transplants. Because of the way the media defines 'news,' celebrities who need or receive transplants get widespread media coverage. Although these celebrities can personally vouch for the importance of organ donation, to the

public, this can be interpreted as merely vested interest. This helps to explain the finding that the public explicitly does *not* want to learn about organ donation from celebrities (14). This cynicism is expressed in the following exchange:

Dyad 31

Person 1: But, like, the most stuff I see is, like, somebody's, like, brain dead and they donate something. It's not usually, like, somebody who just died of, I don't know. So, who knows? It's usually, like, they're brain dead or something and their family donates their organs. I don't know. And then, I see, like, famous people getting the organs, like every other day. And I'm, like 'Where you get that lung from?' You know what I'm saying? Like, do you...like, you definitely won't know this. Like, yesterday, you got a whole new lung. That's really not fair. So...I don't know. [...]

Person 2: Money talks, I guess.

Person 1: Money does talk. Money's loud.

Person 2: Very, very loud. Yeah.

Doctors manipulate organ allocation system. Although there was a general distrust of doctors, medical institutions, and the organ allocation system, one specific case was used as evidence to support misgivings about doctors and the medical system. Six months before this study was conducted, a young Mexican woman, Jesica Santillan, was the victim of a 'botched' transplant at Duke Medical Center. Just days after the original attempted transplant, a new heart-lung combination was procured and a second transplant was attempted to try to save the life of Santillan, who was now in a coma. She died shortly after the second transplant. Although a number of months had passed since this tragic error, study participants had a remarkably clear memory of the incident.

Dyad 1

Person 1: Well there was the girl who had something screwed up. What was it, a year ago, or something? Remember her? She...-Heart/lung or something and they put the wrong type in...?

Person 2: Oh, yeah. The girl from Mexico.

Person 1: Yeah. So that was...

Person 2: Yup.

Person 1: So she was

Person 2: [Someone]

Person 1: no celebrity

Person 2: [Someone] put, like, the wrong

Person 1: [blood type]

Person 2: like it was, yeah, blood type on the form, like a secretary or sta... some staff person did that, and she died.

Person 1: Yeah, she didn't make it.

Person 2: So that's really beat.

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, break 'em if they feel the need.

It should be noted that an examination of the media coverage of the Jessica Santillan case shows that the media expended little to no effort trying to explain the organ allocation system, electing instead to focus on the more sensational aspects of the evolving story (15). This is worth mentioning as the general public relies on the media for its information about organ allocation, lacking personal experience or motivation to actively seek this information from primary sources such as area OPOs, UNOS, or the Coalition for Donation.

Transmutation of recipients. A number of people believe that recipients take on the traits of their donors in some kind of mysterious, spiritual transference.

Dyad 18

Person 1: And, uh, the other thing is sometimes you see shows where people got a heart and they start to like different foods or they have dreams that you know, like, the person whose heart they got would maybe have dreams about her.

Person 2: [Yeah.] Oh, yeah.

Person 1: And then they contact the parents and they say 'Oh, we had this dream about...or I had this dream about some tree or hill or something. Is it in...?' And then the parents say 'Oh, yeah. That's his favorite place.'

Person 2: [That was his favorite,] yeah.

Dyad 15

Person 2: [Yeah.] And then they're, like, 'Oh, like, I got...I never liked oatmeal raisin cookies until I got his heart in me and now I like them.'

Person 1: Did you really see that?

Person 2: [I don't know.] That's just

Person 1: [I've] seen stuff like that, but that's...but that story was actually a nice story, not, like a...like a hoakie story.

Positive coverage of organ donation in the media

Positive images of organ donation do exist in the media. However, positive images are not as memorable as negative images, especially when the public already feels somewhat uneasy about the prospect of donating their own or a loved one's organs. Further, positive coverage is often unidimensional, focusing on heart-warming emotional stories of a life saved because of organ donation, or the tear-filled reunion between donor family and recipient. Indeed, these were the only positive media images or stories recounted by participants. Although it is important to show the public that 'ordinary' people receive transplants and it is equally important to model the desired behavior of consenting to donation, the OPO community needs to work with the entertainment industry to stop undermining efforts to promote organ donation. Negative images and information are not simply more memorable, but the fears that they touch upon are highly diverse. Providing the public with so many different (though false) reasons to not donate is a tragedy for the thousands of people waiting for transplants.

Discussion

Our research has shown that there are barriers to donation that are being actively promoted by consistently negative, sensationalistic portrayals of organ donation in the media. It is far too easy for people who are well-informed about organ donation to dismiss far-fetched portrayals of organ donation in the media as being 'only entertainment.' We tell ourselves that rational people could not possibly believe that doctors would kill their patients to sell their organs or that a transplanted hand could turn a recipient into a serial killer. However, such media portrayals seem to deepen ambivalence about organ donation in spite of consciously (generally) favorable attitudes toward organ donation.

The findings from our current study lead us to advance several recommendations for the organ procurement and transplant professional community. First, forming a coalition of concerned professionals and members of the public that can be mobilized quickly to action may be of real

benefit. Pressuring the media to stop creating the most sensationalistic stories or movies that exploit public fears will send the message that people are paying attention and this may help convince writers and producers that they need to portray organ donation more accurately. To put this in another perspective, no other group of people affected by an important health issue would tolerate the sensationalistic, negative, and patently false treatment that organ donation has received in the media. As a result, AIDS activists, breast cancer advocates, and many others have successfully changed the course of false or sensationalistic media coverage.

Second, employing media consultants with access to the entertainment media may be able to help counter the negative framing of organ donation in the media. There are a number of health-related organizations that work with entertainment media to insert pro-social storylines into mass media programming using a variety of strategies to promote key messages about a particular health issue (16). In an informal review of webpages with links to writers' resource pages for two dozen health-related organizations, not a single one mentions organ donation. Most disturbingly, the CDC's own website, which provides information on over 130 different health issues, does not include organ donation and transplantation. Clearly, the organ procurement community must improve outreach to the CDC as well as to organizations that compile informational resources for producers and writers.

Third, more powerful national campaigns must be developed to counter the actual barriers to the willingness to donate. Social science research has consistently pointed to several key myths that are believed by a majority of Americans, the belief in which statistically discriminates between those who are willing to donate and those who are not. It should be noted, of course, that general knowledge about organ donation is low among both donors and non-donors (11). Thus, it is important to target only the specific knowledge that is known to impact the willingness to donate. As might be expected from the results of this study, specific facts that must be emphasized include the reasons why a black market for organs does not exist in the USA, the 'checks and balances' in the organ procurement and allocation systems that prevent doctors themselves from determining who receives organs, the separation of emergency room trauma surgeons and transplant surgeons, that brain death is determined by more than one doctor and the ways in which brain death is distinct from a coma.

Well-designed, theoretically grounded, and specifically targeted campaigns have a tremendous potential for increasing the rate of organ donation. Unfortunately, this is likely to require a fairly high level of funding, especially to create a national campaign that utilizes paid media instead of PSAs run in the very early hours of the morning. However, if augmented by an entertainment education approach in cooperation with Hollywood and television writers and producers, considerable advances in the promotion of organ donation could be made even with limited funds.

Future research

An important question is raised in this research: Do family members simply remember gruesome images presented in a few isolated media programs? Do they draw inferences that are utterly unwarranted, victims of their own over-active imaginations? Or does the media industry indeed exploit the public's worst fears for profit? A major examination of the content of the media can provide an answer these questions. Undoubtedly, this will be a highly ambitious endeavor. The information that results, however, can help the OPO community more directly target those media which are responsible for the most problematic portrayals of organ donation and transplantation. Moreover, understanding the exact nature of these portrayals will allow the OPO community to focus their energy on countering those myths that are most frequently exploited. This is particularly important because persuasion research has consistently shown that negative information that is not countered is easily believed (17), especially when that information is embedded in narrative form (as with movies or other entertainment programming) because people suspend disbelief as part of their involvement with the story (18, 19).

Conclusion

It is clear that the media is the source of (or exacerbating factor contributing to) many public fears about organ donation. The media was frequently cited as a source of information about organ donation, predominantly to the detriment of support for donation. Many other organizations representing a wide variety of health issues use the strategy of 'entertainment education' to promote better understanding of these health issues or to promote a particular health behavior. Daytime serials have been used frequently to promote issues of public health with great effect. Thus, it is particularly alarming that in the spring of 2004,

One Life to Live featured an extended storyline involving a powerful and corrupt surgeon who procured organs from his patients and sold them to the highest bidder. Such portrayals of the medical and organ allocation systems are potentially destructive to the goals of the OPO community.

In addition, it is imperative that national campaigns be developed to counter the messages the public receives from the mass media. Adopting a multi-pronged approach to addressing myths in the media will help make the job of educating the public about organ donation much easier. However, it is probably time to refine organ donation messages to address the public's deep-seated fears about the medical system and the organ allocation system – the primary reasons for not wanting to donate.

Not all important reservations about donation were represented in the context of discussions about what was heard in the media – but participants' discussions of the mass media do demonstrate that some of the most pervasive myths about donation are not only being promoted through the mass media but that these portrayals of donation also have a very real impact on the willingness to donate. This may further impact the willingness of their family members to donate, to the extent that this information is raised in discussions about donation.

Much is made about public education on the issue of organ donation. However, we are 'swimming upstream' when we have to struggle with the negative images constantly promoted in the mass media. Even worse, we have been largely unconscious of the nature and content of the media's messages about donation, making our job even more difficult. Further studies of the media's portrayal of organ donation will undoubtedly assist the OPO community in constructing more effective public education campaigns.

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Appendix A

Questions used to prompt family discussion about organ donation

1. We would like you to discuss organ donation. We are defining organ donation as providing consent to allow your vital organs and/or tissues to be removed after your death for medical purposes.
Please discuss with one-another your thoughts and feelings about organ donation. 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?