

# Facts versus 'Feelings'

## How Rational Is the Decision to Become an Organ Donor?

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### Abstract

Researchers are already aware that decision making about health issues is not necessarily driven by rational or cognitive-based decision-making processes. This appears to be especially true for the decision to donate organs. Although hints about what is actually driving the decision-making process are scattered throughout the literature, noncognitive factors have not been tested systematically. Structural equation modeling of data gathered from 4426 participants at six different geographic locations in the United States demonstrates that cognitive-based factors (such as knowledge about donation) are less influential on the decision to donate than noncognitive variables such as the desire to maintain bodily integrity, worries that signing a donor card might 'jinx' a person, and medical mistrust.

### Keywords

- *health campaigns*
- *health communication*
- *organ donation*
- *organ transplantation*

NO DOUBT, the 94,647 people on the transplant waiting list ([www.unos.org](http://www.unos.org)) and their corresponding hundreds of thousands of family members wonder not only whether a life-saving transplant will come in time, but why more Americans do not donate. After all, donors have already died; why not save the lives of others after one's own death?

Similarly, many people who have already signed donor cards cannot comprehend why anyone would not donate. A number of participants in a recent qualitative study (Morgan, Harrison, Long, Afifi, & Stephenson, in press) expressed bewilderment at any reluctance to donate. In a conversation about organ donation, a husband and wife had the following exchange:

Donna: To me, it's such an obvious ... if you're not using them, let somebody else have them.

Mike: Yeah, I ... I don't know, honestly, what to think about people that say 'Oh, yeah, I'm not an organ donor,' 'cause I'm like 'Why?' (Dyad 35)

So, what predicts—and prevents—people from signing donor cards? Certainly not attitudes toward organ donation: an overwhelming majority of Americans favors organ donation, according to the latest Gallup poll and multiple social science studies

(Gallup Organization, 2005; Horton & Horton, 1990; Morgan & Miller, 2002b). Awareness of the need for organs for transplant is similarly high (Gallup Organization, 2005; Horton & Horton, 1990, 1991). Knowledge about organ donation has been shown to be a weak predictor of the willingness to donate, even when measures are composed of only those specific knowledge questions that distinguish between donor and non-donor status (DeJong et al., 1998; Morgan, Miller, & Arasaratnam, 2003).

A social scientific approach to the study of organ donation that presumes rational decision making has failed to help us fully understand the wide range of responses to the idea of donating one's own organs. We have yet to identify and study a number of variables that may impact Americans' responses to donation. By examining both the traditional 'rational', cognitive-based variables and more visceral or spiritual noncognitive variables, we may begin to get a clearer picture of the issues that prevent people from consenting to donation. This is an important prerequisite for building effective persuasive campaigns that have the potential to save lives.

In this manuscript, we report the results of a six-state study of variables that impact the decision to donate among a diverse population. Our report of

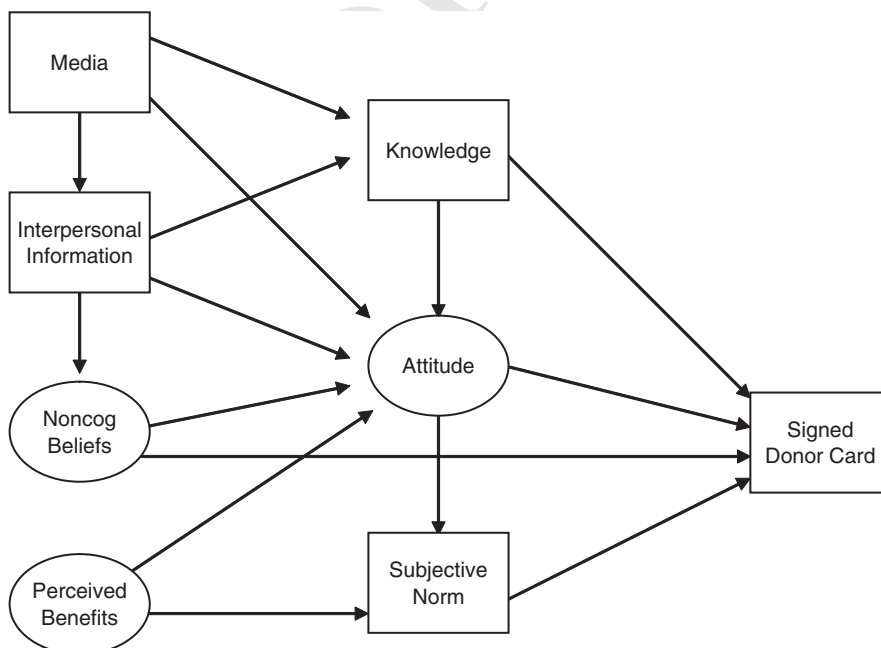


Figure 1. Hypothesized structural model

these results is accompanied by a test of the model of the relationship between key variables. This study is driven, in part, by the persistent calls of social scientists for research that is rigorous, grounded in theory, goes beyond simple assessments of attitude/knowledge/behavior, focuses on multicultural populations and adult samples, and that is accompanied by sophisticated analytic techniques such as structural equation modeling (Horton & Horton, 1990, 1991; Morgan, Miller, & Arasaratnam, 2002; Radecki & Jaccard, 1999). The results point to a set of strategies that should be adopted by health communication researchers who seek to promote organ donation or other health behaviors that may be impacted by non-rational decision making.

### Theoretical foundations

Our initial theorizing is grounded in the theory of reasoned action (TRA) (Fishbein & Ajzen, 1975), which has been expanded upon and tailored to the area of organ donation by Morgan and colleagues (see Morgan et al., 2002 for a description of the Organ Donation Model, or ODM). Traditional TRA variables include knowledge, attitude, social norms, and behavioral intentions, while ODM includes additional variables such as exposure to information and spiritual and cultural values. These models form the basis for our theorizing about the impact of largely ignored noncognitive variables on the willingness to donate organs. The variables comprising the TRA and ODM and findings pertaining specifically to organ donation are described below. Fig. 1 presents the expanded version of the ODM, which forms the underpinning of the current study.

### Traditional cognitive-based variables

#### *Attitude toward donation*

Most social psychology theories, including TRA, take for granted that attitudes toward an object will shape behavior toward it, so it is not surprising that organ donation researchers first measure respondents' attitudes toward donation. The results of social science research demonstrate that attitudes are indeed a statistically significant predictor of whether people sign a donor card (Horton & Horton, 1990, 1991; Kopfman & Smith, 1996; Morgan, 2004; Morgan & Miller, 2002b; Skumanich & Kintsfather,

1996); however, a close examination of effect sizes reported in these studies shows that the relationship is generally quite weak.

Parisi and Katz (1986) adopted a more sophisticated approach to the measurement of attitudes toward donation. They pointed out that attitudes toward donation do not vary along a single continuum from positive to negative. Instead, they posited that people could simultaneously hold positive and negative attitudes toward donation. It is this balance of positive vs negative attitudes that should be of interest to researchers. Notably, Cacioppo concurred with Parisi and Katz's (1986) proposed bivariate structure of attitudes toward organ donation (Cacioppo & Gardner, 1993).

Unfortunately, 'attitude toward donation' in many seminal social scientific studies has been operationalized as respondents' attitudes toward the abstract notion of organ donation rather than their attitudes toward becoming an organ donor. While there are signs that this is now changing with growing recognition that only attitudes toward the latter position are relevant, it should nevertheless be noted that in most studies on organ donation, 'attitudes' refer to attitudes toward organ donation itself.

#### *Knowledge about organ donation*

As with attitudes, TRA and the ODM presume that an increased level of knowledge will predict a greater willingness to engage in a particular behavior, including the willingness to donate (DeJong et al., 1998; Horton & Horton, 1990, 1991; Morgan et al., 2002, 2003; Radecki & Jaccard, 1999; Sanner, 1994b) even as researchers themselves point out that the effect sizes are generally weak when applied to organ donation (see Morgan et al., 2002; Reubsaet, van de Borne, Brug, Pruyn, & van Hooff, 2001). Some researchers have discerned the specific types of knowledge that discriminates between donors and non-donors (DeJong et al., 1998; Horton & Horton, 1991; Morgan & Cannon, 2003; Morgan & Miller, 2002a). Unfortunately, these findings have yet to be translated into more specifically targeted regional or national organ donation campaigns.

However, specific knowledge about organ donation may result in only marginal increases in the willingness to donate. Sanner (1994b) was among the first to suggest that the true barrier to organ donation is a deeper unease about the underlying issues of organ donation, not low levels of knowledge. A scientific understanding of these issues may be obscured by social scientists' persistent focus on the easily quan-

tifiable knowledge variable. Just as members of the general population frequently state that organ donation is against their religion as a way of shutting down discussion about donation or as a way to avoid having to think about donation (Parisi & Katz, 1986; Sanner, 1994b), researchers may be focusing on 'lack of awareness' or low knowledge levels as a way to avoid thinking about the deeper and messier human motivations that drive decision making.

### *Perceived social norms*

The effect of self-reported perceived (subjective) social norms on the willingness to donate is well established in the literature (Kopfman & Smith, 1996; Morgan, 2004; Morgan & Miller, 2002a; Radecki & Jaccard, 1999; Reubsæet et al., 2001; Saub, Shapiro, & Radecki, 1998) especially within minority populations (DeJong et al., 1998; Lange, 1992; Morgan et al., 2003; Schutte & Kappel, 1997; Stevens, 1998; Toledo-Pereyra, 1992; Wittig, 2001). Interestingly, while some studies point out that those who have talked to family members about donation were more likely to have signed a donor card than those who had not talked to their families, this may be a misleading finding, perhaps as an artifact of student or homogeneous (European-American) samples. For example, Morgan (2004) pointed out that across three large data sets, the numbers of people who are *non-donors* who *have* talked to their families about their wishes are roughly equal to the number of *donors* who *have not* informed family members of their desire to donate.

Disturbingly, other studies have demonstrated that perceived social norms are, in fact, a negative influence on the decision to donate at least for a substantial portion of the population (DeJong et al., 1998; Lange, 1992; Morgan, 2004; Saub et al., 1998; Stevens, 1998). This is an unfortunate irony because the National Coalition for Donation and all regional organ procurement organizations strongly advocate that people engage in family discussions about organ donation. Certainly, we should not discourage people from having such an important discussion; however, we should be cognizant of any possible unintended consequences of this goal.

The desire to avoid talking to family members because of anticipated negative reactions appears to be a function of how knowledgeable the prospective donor is, probably because the donor is likely to be called upon to defend his or her decision against prevailing myths (Morgan, 2004; Morgan et al., 2003). In Morgan et al. (2003), path analyses of the

relationships of attitude and knowledge to donor card status and whether people had talked to families about donation demonstrated that family discussion was driven by knowledge about donation, while the personal decision to donate was driven by attitudes toward donation.

### *Interpersonal and mass media sources of information about organ donation*

Obviously, accessibility to and memory of information should influence the decision to donate. There are a number of sources of information important to the decision to become a donor, including general news coverage, public service announcements, movies/TV, family members, friends, medical professionals, and personal experience or involvement with donation (Conesa et al., 2004; Guadagnoli et al., 1999; Morgan & Cannon, 2003). Knowing someone who has received a transplant has been reported to be a positive influence on the willingness to donate (Creecy & Wright, 1990; Rubens, 1996) but statistically, this is likely to be a very small portion of the population; moreover, it is not a variable that we are able to control for the purposes of public organ donation campaigns.

Curiously, McNamara et al. (1999) reported that information does not lead to behavior, especially for African Americans. This was echoed by the findings of Morgan et al.'s (2003) study where the variable of 'information sources' proved to be non-significant in path analysis of the variables in the Organ Donation Model. One possible reason that has been rarely examined is that information in the media may be negatively skewed, thus leading to a negative impact on the willingness to donate. At the very least, 'information' in the general media environment (and even the interpersonal environment where a negative contagion effect of false information can occur) may be contributing to null effects in the literature. A second possible reason is because the 'information' that many people are getting from the media about organ donation is false. Recent research has demonstrated that entertainment television consistently fuels belief in common myths about donation (Morgan, Harrison, Chewing, DiCorcia, & Davis, 2007) and that these myths (which often includes a recital of the plots that support these negative beliefs) make their way into interpersonal conversations about organ donation (Morgan et al., 2005). Thus, because the media is the only source of information about organ

donation that the public is exposed to on a regular basis, information from the media forms the foundation of what is discussed in interpersonal contexts.

There are a number of variables that are not cognitive in nature that have been identified in a surprisingly large number of studies. Most studies discuss these variables almost as an important afterthought; certainly none except Sanner (1994b) set out to study the spectrum of noncognitive variables that can influence the decision to donate. Nonetheless, the influence of these beliefs can be very powerful. According to Parisi and Katz, 'For some people ... these beliefs may rise as rationalizations for an antipathy against donation. That is, they may provide a cognitive overlay for less rational sources of fear, such as superstition' (1986, p. 577). In other words, responses to survey-based studies that presume rational evaluation of the prospect of donating one's organs may be reporting cognitive responses that are actually thinly veiled noncognitive reactions. Unfortunately, noncognitive variables impacting the decision to donate have not been systematically reviewed, which is a significant oversight because it prevents researchers and practitioners from developing more sophisticated campaigns to address all barriers to donation.

### **Noncognitive variables**

For the purposes of this study, noncognitive variables are defined as those that are related to reasoning, which have been formed without direct experience (or the direct experience of significant others). These are often subconscious beliefs that people find hard to articulate (Sanner, 2001). Such beliefs should be in no way confused with 'irrational' ideas or decisions. Responses driven by deep, or even primal, motivations can make sense within their own framework of reference; there simply is no way to objectively determine the truth or falseness of noncognitive beliefs. For example, because no one truly knows what happens to the spirit after death, we cannot assert that the body need not be whole in order to have an afterlife. Our only option is to reference scriptures that may serve to support organ donation. For example, the Bible states in II Corinthians that Christians will get a new, perfect body in heaven. Thus, we are nonetheless able to create arguments and counterarguments that are not based on directly knowable information.

Similarly, blood and death taboos have been described in the literature in cultural anthropology

but are rarely acknowledged in the health psychology or health communication literatures as variables that might impact the success of health campaigns. Most cultures have proscriptions (or at least strict rules and rituals) regarding the handling of dead bodies. Naturally, such taboos once served an important societal function related to hygiene (and still do in traditional societies). However, few studies acknowledge that taboos related to death and dead bodies may impact decisions about organ donation even in industrialized societies. Morgan and colleagues (2003) have termed visceral responses to organ donation the 'ick' factor and the constellation of fears and superstitions stemming from the violation of blood and death taboos the 'jinx' factor.

### ***Ick factors***

Ick factors are those related to a basic disgust response to the idea of organ procurement or transplantation. Concerns about having one's body 'mutilated' or 'defiled' after death are common (Kopfman, Smith, Yun, & Hodges, 1998; McConnell, 1999; McNamara et al., 1999; Parisi & Katz, 1986; Sanner, 1994b; Skumanich & Kintsfather, 1996). According to Parisi and Katz,

fear of posthumous mutilation ... seem[s] to be deeply rooted in the unconscious and to have relatively little cognitive content ... it seems improbable that misconceptions about the surgical procedure and the extent of alteration of the body [as a result of organ procurement] are an important factor in the fear of mutilation. More likely, this emotion involves religious, mystical, or superstitious beliefs ... (1986, p. 576)

However, one person's 'religious or mystical' beliefs are another's simple belief in 'having respect for the dead' (Plawecki, Freiberg, & Plawecki, 1989). Importantly, there are also more visceral responses to organ donation. Profound squeamishness or disgust at the idea of having one's organs inside of another person (Gordon, 2001; Sanner, 2001; Wittig, 2001) may result from the sense that that organ donation is not 'sanitary' (Braun & Nichols, 1997). Anecdotally, several of the authors have encountered people in the course of community outreach events who simply state, 'It's just kind of gross.' It is this fundamental disgust response that most centrally defines the 'ick factor' rather than more spiritual or religious concerns about maintaining bodily integrity.

### *Jinx factors*

Jinx factors are those that are related to (unconfirmable or generally unwarranted) fears, anxieties, and superstitions about the misfortune that would result if a person signed a donor card or actually donated his or her own organs. At a basic level, some people believe that it is bad luck to even talk about death (Braun & Nichols, 1997; Wittig, 2001), which is obviously a significant problem for campaigns encouraging people to discuss their wishes about organ donation with family members. Again, community outreach volunteers report that they commonly encounter resistance to signing a donor card because people sometimes fear they will die shortly thereafter. Such fears are probably aggravated by well-intentioned news stories about young people killed in tragic accidents who only days or weeks earlier had told family members they wanted to be donors. Although the fear that death may be declared prematurely might legitimately be viewed as a 'jinx' factor, this particular fear may also stem from a mistrust of the medical system; thus, questions about the fear of the premature declaration of death are not used to operationalize measures of the belief in a 'jinx factor' negatively associated with the willingness to donate.

### *Medical mistrust/premature declaration of death*

The citation of medical mistrust as a barrier to organ donation is truly ubiquitous (Davidson & Devney, 1991; Lange, 1992; Rene, Viera, Daniels, & Santos, 1994; Sanner, 1994b; Stevens, 1998; Thompson, 1993; Toledo-Pereyra, 1992; Youngner, 1992). Although medical mistrust is an especially formidable barrier within the African American population (see Siminoff & Arnold, 1999), Morgan and her colleagues (2003) demonstrated that medical mistrust is a powerful influence for people of all ethnic backgrounds. We acknowledge that listing medical mistrust as a 'noncognitive' factor could be seen as questionable, especially for African Americans, who still live with the legacy of the Tuskegee experiments. However, in our efforts to develop a measure of medical mistrust that is equally valid and reliable for both African Americans and European Americans, we have included items that reflect cynicism, even paranoia, about the medical establishment and its willingness to sacrifice the well-being of patients in favor of more self-serving goals. This measure forms the basis of our assumptions about how medical mistrust can be noncognitive in nature.

While some readers (and even most of the authors) are likely to consider medical mistrust as nothing more than a healthy skepticism based on well-publicized periodic news exposes, the vast majority of the population has not experienced such abuses themselves, nor have any of their close friends or family members. Moreover, deep medical mistrust can work against a person's own well-being, as evidenced by the number of people who postpone medical care until illness is too advanced to treat.

Perhaps the most common fear related to organ donation is that doctors will kill patients in order to obtain their organs. This fear is cited as a significant barrier to organ donation across both qualitative and quantitative studies and among African Americans, Asian Americans, Latinos, and European Americans alike (Davidson & Devney, 1991; Lange, 1992; McNamara et al., 1999; Morgan, 2004; Morgan & Cannon, 2003; Morgan et al., 2003; Parisi & Katz, 1986; Reitz & Callender, 1993; Siminoff & Arnold, 1999; Spigner et al., 1999; Toledo-Pereyra, 1992; Youngner, 1992). The fact that no allegations of premature declaration of death for the purposes of organ procurement have ever been reported makes such a widespread fear especially noteworthy.

### *Bodily integrity*

Some fears about the consequences of being an organ donor are closely related to the belief in the need to maintain the integrity of the body after death or face serious afterlife consequences. The desire to preserve bodily integrity is associated with beliefs that a person would have to endure eternity or be reincarnated without organs (Braun & Nichols, 1997; Rubens & Oleckno, 1998), or worse, that an afterlife existence would be precluded entirely as a result of having had one's organs removed (Parisi & Katz, 1986). For those that believe in life after death, this fear would be profound. However, such fears seem to persist in spite of the fact that all major religions have either issued statements of outright support of organ donation or at the very least reassure adherents that organ donation is a matter of individual conscience and is not precluded by scripture.

### *Perceived benefits of donation*

Thus far, all of the noncognitive factors reviewed have presumed negative effects on the willingness to donate. There are, however, perceived benefits to becoming an organ donor after death that have a positive effect on the willingness to donate. Although

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Table 1. Response rate by university

| <i>University</i>                       | <i>Sample size</i> | <i>Number of responses</i> | <i>Response rate (%)</i> |
|---|--------------------|----------------------------|--------------------------|
| Pennsylvania State University           | 3917               | 1366                       | 34.9                     |
| University of North Carolina, Charlotte | 1033               | 440                        | 42.6                     |
| University of Alabama                   | 1410               | 566                        | 40.1                     |
| University of Arizona                   | 1711               | 635                        | 37.1                     |
| Rutgers University                      | 2074               | 554                        | 26.7                     |
| Texas A & M University                  | 3603               | 789                        | 21.9                     |
| Total                                   | 13,748             | 4350                       | 31.6                     |

(non-living) organ donation occurs only after the donor has died, people do, in fact, perceive benefits that will be garnered for themselves as a result of having donated their organs. Parisi and Katz's (1986) study included survey items related to a perceived sense of being a hero after death because one has saved the life of another person, and their own continuing physical or spiritual survival after death through one's organ recipients. These perceived benefits are closely linked to a basic human need for some kind of sense of immortality, as described by terror management theory (Greenberg, Solomon, & Pyszczynski, 1997). This noncognitive motivation may provide a fruitful avenue for the development of future organ donation campaigns through messages that emphasize the symbolic survival of donors after death (e.g. a donor is an 'angel').

As we have demonstrated, previous research has identified a wide array of both cognitive and noncognitive variables that may impact the willingness to donate organs. However, these variables have not been merged into a comprehensive model for the willingness to donate organs (see Fig. 1). This model represents the full range of variables identified by the extant research across a variety of disciplines as well as those represented in prominent theories of behavior change. As with the theory of reasoned action, both attitudes and subjective norms are predictors of intent to sign a donor card. However, the organ donation model in Fig. 1 also provides a representation of the noncognitive variables that is often absent from behavioral models. The organ donation model, based on previous research, also provides for a direct impact of knowledge on one's signing of a donor card. We believe that in order to create effective campaigns for both national audiences as well as specific communities touched by organ donation (e.g. African Americans), it is vital that all important variables affecting the decision to donate be identified and their relationship to one another established.

## Method

### *Participants and procedures*

A random sample of 8 percent of the students, faculty, staff, and administrators from each of six large universities in the United States was obtained. Registrar offices and payroll services provided these data. Individuals received the survey, a note on university letterhead inviting their participation, and a postage-paid return envelope and were offered a t-shirt or travel mug in exchange for their participation. The surveys were preprinted on optical scanning forms designed to facilitate data entry. The survey contained 68 questions plus an additional seven demographic items (questions not pertaining to the current study are not listed in the measures section below). The survey could be completed in five to seven minutes. A month after the initial mailing, all participants received a follow-up reminder survey. Unfortunately, even with this reminder, the response was low, ranging from a low of 22 percent to a high of almost 43 percent (with an overall average of 32 percent) (see Table 1). Hence, convenience sampling was used to collect an average of 250 additional surveys from centralized campus locations (e.g. student union buildings) on all participating campuses. Follow-up analyses determined that survey responses on the variables used in this study did not vary significantly based on method of data collection.

The six universities, which were located in geographically diverse areas of the United States and represented both urban and rural locales, included: University of Arizona, University of Alabama, University of North Carolina-Charlotte, Pennsylvania State University, Rutgers University, and Texas A&M University. The institutional review boards from all six universities approved this research.

We received a total of 4426 completed surveys. Of the participants, 64 percent were students or graduate students, 23 percent were staff; 9 percent

were faculty, and 3 percent were administrators. Most respondents were affiliated with Penn State (31%) while the fewest were affiliated with UNC-Charlotte (10.1%). Additionally, 62 percent were female; 54 percent were ages 18–25; 75 percent were European American, 9 percent Asian, and 6 percent African American, 2 percent were American Indian/Alaskan, 6 percent were Latino, and 2 percent were other or unknown.

## Measures

**Behavior—signing donor card** Participants responded either *yes* or *no* to ‘I have signed an organ donor card or indicated on my driver’s license that I want to be a donor.’

**Knowledge** Knowledge was assessed with six questions to which respondents could answer either *yes* or *no*. Questions included, ‘It is possible for a brain-dead person to recover from his/her injuries’ and ‘People who choose to donate a family members’ organs end up paying extra medical bills.’ Correct answers were summed into a score ranging from zero to six. The mean number of correct responses was 2.58 (SD = 1.56).

**Attitudes** Three items comprised participants’ attitude toward organ donation. Measured on a seven-point scale (1 = *strongly disagree*; 7 = *strongly agree*), items included ‘I support the idea of organ donation for transplantation purposes’ and ‘I view organ donation as a benefit to humanity’. This measure was reliable ( $\alpha = .90$ ).

**Interpersonal sources** Participants were asked, ‘Where have you seen, heard, or read about organ donation?’ Participants could mark any of the following sources of interpersonal information: family or friends, someone you know or met who has a transplant, work, religious service, and a presentation. Responses were added to create the interpersonal sources scale.

**Media sources** Participants were asked, ‘Where have you seen, heard, or read about organ donation?’ Participants could mark any of the following media sources: television, radio, newspaper, posters, magazines, and billboards. Responses were added to form the media sources scale. We posit that the amount of information obtained through the media will influence not only attitudes and knowledge about organ

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donation, but will serve as a stimulus for interpersonal communication about the issue of donation.

**Subjective social norms** Two questions were used to measure perceived social norms. Following Fishbein and Ajzen (1975), the responses were multiplied to create the subjective social norm variable. The first question, presented on a seven-point scale anchored by *not very much* and *very much*, was ‘Think of the most important person in your life (an adult). Do you think this person is in favor of organ donation?’ The second question, presented on a seven-point scale anchored by *definitely no* and *definitely yes*, was ‘How much does his/her opinion about organ donation matter to you?’ The second question was recoded from –3 to 3 in order to get an accurately valenced score for this variable.

**Perceived benefits** Perceived benefits of organ donation were assessed with three items. Using a seven-point scale (1 = *strongly disagree*; 7 = *strongly agree*), sample items included ‘Organ donors are heroic because they save lives’ and ‘Donating organs would allow part of me to live after I die.’ The measure’s reliability was  $\alpha = .67$ .

**Bodily integrity** Bodily integrity was measured with three items on a seven-point scale (1 = *strongly disagree*; 7 = *strongly agree*) and evidenced good reliability ( $\alpha = .86$ ). Items included ‘Removing organs from the body just isn’t right’ and ‘The body should be kept whole for burial.’

**Jinx factor** Jinx factor was measured with four items on a seven-point scale (1 = *strongly disagree*; 7 = *strongly disagree*) and was reliable ( $\alpha = .83$ ). Sample items included ‘The surest way to bring about my own death is to make plans for it like signing an organ donor card’ and ‘People who donate their organs risk displeasing God or nature.’

**Ick factor** Ick factor was measured with four items on a seven-point scale (1 = *strongly disagree*; 7 = *strongly disagree*) and was reliable ( $\alpha = .85$ ). Sample items included ‘The idea of organ donation is somewhat disgusting’ and ‘Organ donation leaves the body mutilated and disfigured.’

**Medical mistrust** Medical mistrust was measured with four items on a seven-point scale (1 = *strongly disagree*; 7 = *strongly agree*) and evidenced good reliability ( $\alpha = .84$ ). Items included ‘Hospitals



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Table 2. Correlations and descriptive statistics

| Variable     | 1     | 2     | 3     | 4     | 5     | 6     | 7     | 8     | 9     |       |       |
|--------------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|
| 1. Media     | (1.0) |       |       |       |       |       |       |       |       |       |       |
| 2. IP Info   | .40   | (1.0) |       |       |       |       |       |       |       |       |       |
| 3. MedMis    | -.02  | -.12  | (.84) |       |       |       |       |       |       |       |       |
| 4. Jinx      | -.10  | -.17  | .47   | (.83) |       |       |       |       |       |       |       |
| 5. BodInteg  | -.10  | -.16  | .45   | .69   | (.86) |       |       |       |       |       |       |
| 6. Ick       | -.12  | -.17  | .46   | .63   | .62   | (.83) |       |       |       |       |       |
| 7. Benefits  | .10   | .14   | -.07  | -.06  | -.15  | -.18  | (1.0) |       |       |       |       |
| 8. Knowledge | .08   | .15   | -.33  | -.21  | -.20  | -.21  | .11   | (1.0) |       |       |       |
| 9. Attitude  | .09   | .13   | -.22  | -.32  | -.41  | -.37  | .26   | .08   | (.90) |       |       |
| 10. SubjNorm | -.02  | -.03  | -.03  | -.05  | -.06  | -.04  | -.06  | .06   | -.01  | (1.0) |       |
| 11. Card     | .03   | .15   | -.23  | -.29  | -.34  | -.31  | .14   | .15   | .23   | .05   | (1.0) |
| Mean         | 2.18  | 1.00  | 2.47  | 1.61  | 1.81  | 1.98  | 4.64  | 2.57  | 6.24  | 4.06  | .57   |
| SD           | 1.66  | 1.06  | 1.31  | .98   | 1.19  | 1.13  | 1.43  | 1.56  | 1.16  | 3.62  | .49   |

Note:  $N = 4426$ . All correlations above 0.1031 are statistically significant. Coefficient alpha is presented in the parentheses on the diagonal for all multiple item scales. All other values of 1.0 refer to single-item measures. Medical mistrust (MedMis), Jinx factor (Jinx), bodily integrity (BodInteg), and Ick factor all were second-order factors loading on the latent construct 'Noncognitive beliefs' in Figs 1 and 2

sometimes prescribe medications as a way of experimenting on people without their knowledge or consent' and 'Sometimes, medical procedures are done on people without their consent.'

## Results

### Model testing

The model in Fig. 1 was tested using structural equation modeling using full-information maximum likelihood estimators in EQS 6.1 for Windows. A covariance matrix was computed by EQS from the raw data. Because multivariate distributions were nonnormal (Mardia's normalized estimate = 337.6), maximum likelihood with robust estimators were used to estimate the model. Table 2 provides a correlation matrix and descriptive information of each variable. For missing data, multiple imputation using the Expectation Maximization algorithm was used (Schafer & Graham, 2002).

Omnibus model fit was evaluated with robust statistics including the Satorra-Bentler  $\chi^2$ -distributed goodness of fit test, the comparative fit index (CFI), and the root mean squared error of approximation (RMSEA). Cutoff values of .90 or higher are preferred (Hu & Bentler, 1999; Marsh, Hau, & Wen, 2004). For RMSEA, values below .08 are indicative of adequate model fit while values below .05 are indicative of good model fit.

Most variables in the model were specified using the hybrid approach (Holbert & Stephenson, 2002;

Stephenson & Holbert, 2003). Specifically, medical mistrust, jinx factor, ick factor, bodily integrity, perceived benefits, and attitude toward organ donation were specified as latent variables defined by their individual items respectively. Medical mistrust, jinx, ick, and bodily integrity are latent variables loading on a second-order factor called 'noncognitive beliefs'. Media sources, interpersonal sources, and knowledge reflect additive indexes specified as a single-item observed composite. Social norm was specified as a single-item observed composite comprised of a multiplicative term. Finally, signing a donor card was specified as a single-item variable. Table 3 presents the results of a logistic regression of the predictor variables on signing a donor card.

Model estimation occurred in two steps (Anderson & Gerbing, 1988). Once the measurement model was specified, estimated, and found consistent with the data, then the structural model was specified and estimated. The measurement model was consistent with the data, S-B  $\chi^2 = 2476.67$  (272,  $N = 4426$ ), CFI = .94, RMSEA = .043 (90% CI: .041, .044). When the structural parameters displayed in Fig. 2 were estimated, modification indexes suggested adding a structural path from noncognitive beliefs to knowledge would improve the fit significantly,  $\Delta S-B \chi^2 = 184.8$ ,  $p < .001$ . When this path was added, the model was consistent with the data, S-B  $\chi^2 = 2660.37$  (283,  $N = 4426$ ), CFI = .93, RMSEA = .044 (90% CI: .042, .045). The final model with all paths is presented in Fig. 2.

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Table 3. Logistic regression of predictor variables on signing a donor card

| Predictor   | B      | SE B | Wald  | Odds ratio |
|---|--------|------|-------|------------|
| <b>Block 1</b>  |        |      |       |            |
| Caucasian   | .92*** | .09  | 98.02 | 2.52       |
| African American  | .09    | .17  | .31   | .58        |
| Gender (1 = male)   | .08    | .08  | 1.20  | 1.09       |
| Step $\chi^2$ (d.f. = 3, N = 4426) = 289.26, $p < .000$ , Cox-Snell $R^2 = .069$ ;  |        |      |       |            |
| Nagelkerke $R^2 = .09$  |        |      |       |            |
| <b>Block 2</b>  |        |      |       |            |
| Medical Mistrust  | .04    | .03  | 1.10  | .97        |
| Jinx  | .01    | .06  | .01   | .99        |
| Bodily Integrity  | .32*** | .05  | 48.50 | .73        |
| Ick Factor  | .24*** | .04  | 31.69 | .78        |
| Knowledge   | .06*   | .03  | 1.06  | 1.06       |
| Media Exposure  | .08**  | .02  | .92   | .92        |
| Interpersonal Sources   | .21*** | .04  | 1.23  | 1.23       |
| Benefits  | .11*** | .03  | 1.12  | 1.12       |
| Attitude  | .15*** | .04  | 1.16  | 1.16       |
| Subjective Norm   | .03*** | .01  | 1.03  | 1.03       |
| Constant  | .77**  | .30  | 6.63  | .46        |
| Step $\chi^2$ (d.f. = 10, N = 4426) = 501.02, $p < .000$ , Cox-Snell $R^2 = .177$ ; |        |      |       |            |
| Nagelkerke $R^2 = .24$  |        |      |       |            |

\*\*\* $p < .001$ ; \*\* $p < .01$ ; \* $p < .05$

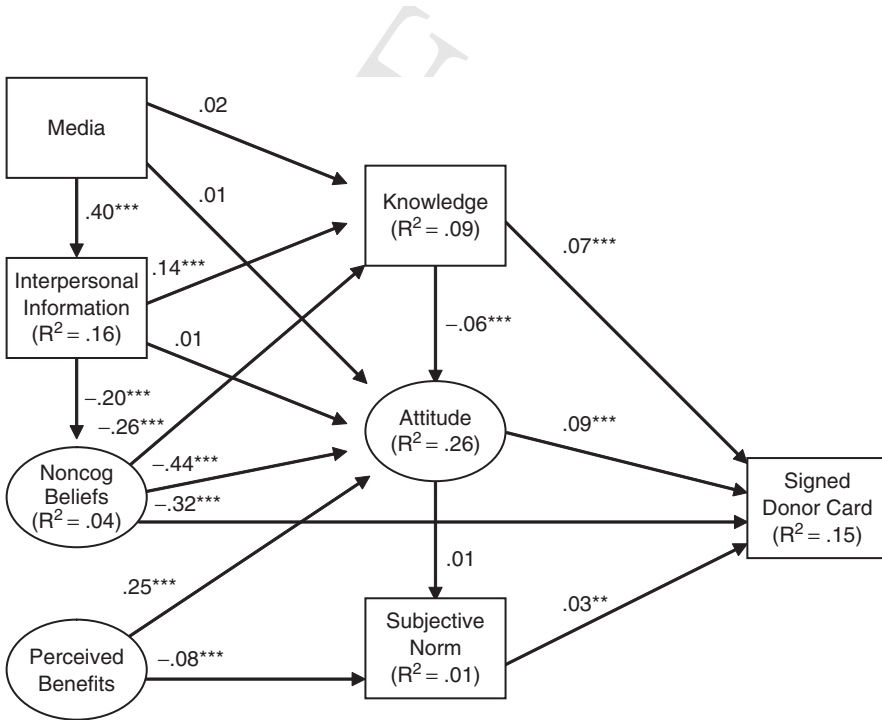


Figure 2 Hypothesized model with structural path coefficients  
\* $p < .05$ ; \*\* $p < .01$ ; \*\*\*  $p < .001$

## Discussion

The results of this study indicate that knowledge and attitudes, both of which we deemed cognitive variables, are relatively weak predictors of donor card status. By far, the most influential direct influence on donor card status is the noncognitive variable reflecting an individual's noncognitive beliefs (comprised of bodily integrity, jinx factor, ick factor, and medical mistrust). Specifically, the greater one's value in protecting their own body, the less likely the individual was to sign a donor card. Noncognitive beliefs was also a strong negative predictor of individuals' knowledge and attitudes toward donation, which in turn influenced donor card status. This may imply that information about organ donation is selectively processed—or not processed at all—because of the powerful influence of noncognitive concerns relating to donation. Finally, attitudes toward organ donation were also a strong function of the perceived benefits of donation (e.g. being a 'hero' by saving lives and the sense that one will live on through donation even after one dies).

Interestingly, the media variable had no significant impact on knowledge or attitudes toward donation, but it did have a strong relationship with interpersonal sources of information. Discussions with friends, family members, and colleagues about organ donation appear to supplement the role of the media in information-gathering about the issue of organ donation. However, these interpersonal discussions may mitigate the strength of belief in the noncognitive factors that negatively influence the willingness to become a potential organ donor. This seems to indicate that bringing the issue of organ donation 'into the light' through interpersonal discussions makes people adopt a less fearful stance toward donation.

As for the remaining variable that corresponds to the theory of reasoned action (one of the foundations of our model), our results indicate that *perceived* social norms does have a weak but significant effect on the willingness to become a potential donor. The term 'perceived' is important here because we are concerned that people may disguise their own opinions about organ donation by projecting disapproval of donation onto important others. Of course, families and spouses often share religious beliefs and norms, so this relationship should be explored further in future studies.

These results are not without surprises. As previously mentioned, reports of the amount of information

received about organ donation, which should impact reasoning about the decision to donate, appear not to predict attitudes toward donation. Although this may be an artifact of our measurement, we are concerned that there is indeed a large amount of information that is reaching the public that is wholly inaccurate or that plays on the worst myths about organ donation. Episodes of legal and medical dramas, daytime serials ('soap operas'), and many popular movies all provide inaccurate information about organ donation. Just as entertainment-education has been effective in changing attitudes and behaviors in support of important health behaviors, it is possible that entertainment-miseducation has been equally effective in creating ambivalence toward donation. Thus, the effect of getting accurate information from some sources may be counteracted by inaccurate information from other sources, creating a non-significant path from media information to knowledge about organ donation.

## Limitations

There are a number of limitations to this study, most notably the low response rate to the survey and the fact that just over 60 percent of our sample consists of students. Generalizability of findings as well as response bias is always a concern when response rates are low; thus, we would expect that people who feel more favorably toward organ donation will be more likely to complete and return a survey. Research has shown (Heberlein & Baumgartner, 1978) that topics themselves can suppress response rates, which we expect is the case with organ donation. Questions about death and dismemberment, especially as they apply to respondents themselves can be considered rather unpleasant. Regardless of the reasons for the low response rate, we make no claims about the representativeness of the sample's behaviors or attitudes regarding donation, only the impact of many different variables on each other and the willingness to donate. Moreover, response rates to mail surveys (including our own) are notoriously low and are common in published social scientific research. In addition, our statistical results from the analysis of responses of our mixed sample of both adults and students closely reflect the pattern of results found in most of the published research in the area of organ donation willingness. The pattern of our findings with regard to cognitive-based variables should not be particularly startling; however, our attention to variables that have been neglected in past research contributes substantially to the literature in this area.

Finally, our measure of information received about donation can be considered a limitation of the study. The measure simply assumes that having a large number of sources is superior to having a greater *quantity* of information from fewer sources, nor is there consideration for the quality or accuracy of the information obtained from each source. Thus, having superficial, redundant, or inaccurate information from a wide variety of sources would lead to a greater information score in our study than having a great deal of accurate, in-depth information from one or two sources.

### *Future research*

For a variety of reasons, there are a number of other noncognitive variables that merit further examination. Most of these variables were not included in the present study because of difficulties involved with operationalization in the face of little extant research and a dearth of reliable, valid measures. Such variables include fears about trait transference between donor and recipient, existential anxiety, empathy, and the illusion of lingering life. Briefly, some people believe that there will be transference of the traits of donor to recipient or that the donor will be responsible for the future (negative) actions of the recipient (Braun & Nichols, 1997; Sanner, 2001). This probably should not be surprising since this notion is played upon frequently in the mass media, in movies (a number of which include plot lines involving people falling in love with the bereaved partner of their donor), as well as news coverage of the emotional reunions between recipients and their donor's family members, where much is often made of whether the recipient now likes to drive fast cars or now mysteriously enjoys the donor's favorite foods.

Although this is rarely mentioned directly, existential anxiety almost surely plays a role in personal reactions to organ donation. Signing an organ donor card or registry requires a person to acknowledge their mortality, and organ donation researchers themselves have pointed out that people want to avoid thinking about death (Ford & Smith, 1991; Skumanich & Kintsfather, 1996). Sanner (1994a) has similarly acknowledged that death anxiety is a significant barrier to becoming an organ donor. Nonetheless, such minimal research is surprising given the support garnered by at least one theory of existential anxiety's influence on behavior (e.g. Greenberg et al.'s (1997) terror management theory).

Finally, there are other anxieties that may not fit under the 'jinx' rubric but are nonetheless

noncognitive in nature. Worries that a dead person will feel pain as a result of organ donation may be more widespread than expected in light of the number of studies reporting this as a significant barrier to donation (Braun & Nichols, 1997; Fernandez, Zayas, Gonzalez, Morales, & Santiago-Delpin, 1991; Lange, 1992; Rene et al., 1994; Spigner et al., 1999; Youngner, 1992). Several studies show that some people believe in 'the illusion of lingering life'; in other words, that a deceased person will be, at a minimum, aware that organs are being procured or that the deceased will be able to feel pain (Sanner, 1994a, 1994b; Stevens, 1998).

Although many key barriers to the adoption of a health behavior may be noncognitive, this does not necessarily mean that they cannot be effectively addressed. People with strong religious or spiritual objections to organ donation often change their position when they realize that major spiritual and religious leaders have issued statements supporting donation, frequently citing the importance of saving the life of another person whenever possible. Additionally, Sanner (1994b) reports that people whose primary barrier to donation was high death anxiety changed their opinion when confronted with both altruistic and fact-based arguments. On the other hand, the sense of being a hero after death or finding satisfaction in having a part of oneself survive death is a positive influence on donation decisions. As mentioned earlier, emphasizing the survival of organ donors through their recipients (literally or symbolically through the gratitude of recipients and families for their life-saving 'angel') may meet the existential needs of some people. These observations dovetail with Parisi and Katz's (1986) recommendations to target affective and cognitive evaluations of organ donation separately because they represent separate, though equally important, evaluation systems (Parisi & Katz, 1986).

Similarly, understanding the medical trust barrier is vitally important. For example, rather than targeting medical mistrust directly, it may be far more effective to explain the various 'checks and balances' in the medical and organ allocation system that prevents doctors from killing patients for their organs or from buying or selling organs on the black market, and that prevents the organ allocation system from giving preferential treatment to rich or famous people or discriminating on the basis of race.

## Conclusion

Researchers have long noted (with frustration) that health-related decision making is frequently driven by noncognitive and even irrational forces. This study explores the forces that shape the decision to donate through the use of structural equation modeling. These findings should be used to develop more sophisticated campaigns to promote organ donation that take into account both traditional cognitive as well as noncognitive variables.

We simply cannot assume that all barriers to organ donation are rational or cognitive in nature. All kinds of decisions, whether about health or other behaviors, are not necessarily based on linear, rational thought processes. Theories of human behavior and behavior change used for public health campaigns must attempt to include noncognitive variables as well as an understanding of how these variables actually affect behavior. Incorporating an understanding of the impact of both cognitive and noncognitive variables on the health behavior being promoted will enhance our likelihood of developing successful interventions.

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