Words versus Actions about Organ Donation: A Four-Year Tracking Study of Attitudes and Self-Reported Behavior

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Historically, the proportion of the American public that expresses positive views about organ donation exceeds the proportion that actually signs an organ donor card (ODC). The public seems to say one thing but does another. In July 1994, The Advertising Council, Inc., in conjunction with the Coalition on Donations, launched a major promotional campaign to educate the U.S. public about organ and tissue donation. This article reports on a four-year study tracking attitude toward organ donation and transplantation and its relationship with direct experience (knowing an organ recipient) and intermediate behaviors. The intermediate behaviors investigated are donating blood and signing an ODC. No significant changes were noted in attitude toward donation, but the proportion of individuals who had signed an ODC increased significantly.

According to the United Network for Organ Sharing (UNOS), the “# 1” issue confronting the transplantation community is the critical shortage of transplantable organs (UNOS, 1998a). In fact, the Coalition on Donations (1998) describes the shortage as a public health crisis. During 1988, 27,805 patients in the United States were on the organ waiting list and there were 4,084 cadaveric donors. By 1996, the number of patients on the waiting list during the year had nearly tripled to 72,836, but the number of cadaveric donors had increased to only 5,417 (UNOS, 1998b). Although 20,354 organ transplants (cadaveric and living) were performed in the United States during 1996, 4,022 patients—about 11 per day—died while on the waiting lists (UNOS, 1998b). It is surprising that the number of cadaveric donors has not increased over the years, as there are over 2 million deaths annually in the United States. While most Americans (85%) indicate that they support organ donation and transplantation (Gallup, 1993), the positive views toward donation expressed by the public are not matched by action.

It is doubtful that the supply of cadaveric organs will ever fully meet the demand. In fact, artificial organs (Basu-Dutt et al., 1997; Kaufmann et al., 1997), xenotransplantation, that is, organs from animals (Arundell and McKenzie, 1997), and even cloned organs (currently banned) may be the ultimate solution. In the meantime, however, the organ donation and transplantation community is actively seeking to increase the number of posthumous donations. One program seeking to increase donations is the national advertising and promotion effort undertaken by the Advertising Council, Inc. and the Coalition on Donations.

National Campaign for Organ Donation

In 1993, The Advertising Council, Inc., (henceforth the Ad Council) and the Coalition for Donations (henceforth the Coalition) developed a multi-media national promotion campaign to educate the public about organ and tissue donation. The overriding objective of the campaign is to increase the number of organ and tissue donors. The campaign was launched in July 1994 with the theme “Organ and Tissue Donation: Share your life. Share your decision.” It stresses the need to sign an organ donor card and to inform family members of that decision. During the campaign’s first year, $33.3 million of media had been donated. In the next year, over $47 million was donated. (Nathan, 1997).

This article reports the findings of a four-year study tracking community attitude and behavior in metropolitan Richmond, Virginia, concurrent with the Ad Council/Coalition campaign. As is the case of the advertising and promotion campaign, the
focus of the study is on posthumous (or cadaveric) donation rather than donation from living donors. Most donations, especially between unknown or unrelated persons, are cadaveric. (See the Appendix for an overview of the cadaveric organ procurement and allocation system in the United States.)

**Study Objectives**

It is believed that prior direct experience is a powerful contributor to attitude formation and reinforcement (Marks and Kamin, 1988; Smith and Swinyard, 1983). In the case of organ donation and transplantation, knowing an organ recipient, therefore, should have a positive influence on attitude toward organ donation and transplantation.

Also, there are several intermediate behaviors between having a positive attitude toward organ donation and transplantation and the ultimate behavior of organ donation. These include such actions as donating blood and signing an organ donor care (ODC). This last behavior indicates the intention of performing the ultimate behavior of becoming an organ donor. It is commonly held that such a demonstrated behavioral intention is a more accurate predictor of actual future behavior than is attitude (Granbois and Summers, 1975; Reibstein, 1978; Warshaw, 1980).

Therefore, the objectives of this study are to measure concurrent with the Ad Council/Coalition campaign:

1. the changes in attitude toward organ donation and transplantation;
2. the relationship to the prior direct experience of knowing an organ recipient; and
3. the more proximate, intermediate behaviors of donating blood and signing an ODC.

**Research Methods**

The study consists of four cross-sectional surveys conducted approximately one year apart in Richmond, Virginia. The first survey was conducted in June 1994, just prior to the July launch of the Ad Council/Coalition campaign, and was repeated in 1995, 1996, and 1997.

**Samples**

A separate probability sample was selected for each survey. The samples consisted of individuals at least 18 years of age residing in the metro telephone calling area. Only persons residing in households in which no one was employed in the healthcare industry are included in this study. Telephone numbers were randomly selected from the telephone directory (current at the time of each study). The +1 sampling technique was employed so that new listings and unlisted numbers could be accessed (Churchill, 1991). It has been shown to be more efficient than random digit dialing designs while not introducing significant bias when the telephone directory is an appropriate sampling frame for a study (Landon and Banks, 1977). Usable responses were obtained from 161 persons in 1994, 126 in 1995, 142 in 1996, and 141 in 1997.

**Measures**

Attitude was measured using an 8-item, 5-point Likert type scale named the DONATT scale (see Table 1). The scale was developed following traditional scale development procedures (Churchill, 1979). The range of possible scale scores is 8–40, with higher scores indicating more positive attitudes. Coefficient α for the scale across all four sample years is 0.83. Test-retest reliability was measured on three convenience samples and ranges from 0.83 to 0.89.

Action was measured by asking participants if they had executed an ODC. In addition, traditional demographic data were collected. Finally, data on the prior direct experience factor of knowing a transplant recipient and the intermediate behavior factor of having donated blood were obtained.

**Analyses and Findings**

The four years of data were examined for variations in response to the DONATT scale using one-way ANOVA. The DONATT scores did not differ significantly over the course of the study (p = 0.773) (see Table 2). That is, there is no evidence of any change in attitude toward donation over the years. Given the millions of dollars in media expenditures, one might have expected a positive change in attitude. While some might suggest that the campaign was a failure, the absence of a control group in this study makes measuring success or failure impossible. It is possible that without the campaign, attitude toward donation might have actually declined. It is also possible that an already high positive response would reduce the chances of obtaining a significant gain in attitude.

A different perspective is gained from an examination of the trend in the proportion of individuals reporting that they had signed an ODC. The proportion reporting that they had signed an ODC has increased significantly over the period of the campaign (p < 0.01) (see Table 3). While there has been no change in the community’s attitude toward donation, there has been a significant increase in the percentage of respondents who say that they have executed an ODC.

Are actions matching words? It appears that they are. The proportion of each sample who had both agreed and strongly agreed with one statement in the DONATT scale: I would donate my organs after my death and who had signed an ODC has shown a strong increase from 39% in 1994 to 63% in 1997 (see Table 4).

To determine if these findings are the result only of sample differences, the samples were compared along demographic and experience characteristics. Wheeler and Cheung (1996) and Pratts (1992) reported that younger, better-educated,
Table 1. DONATT Scale Items

<table>
<thead>
<tr>
<th>Item</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would donate my organs after my death.</td>
<td>5</td>
</tr>
<tr>
<td>I find the idea of organ donation repulsive.</td>
<td>5</td>
</tr>
<tr>
<td>I would not allow the organs of a loved one to be donated.</td>
<td>5</td>
</tr>
<tr>
<td>Organ transplantation is morally justified.</td>
<td>5</td>
</tr>
<tr>
<td>Organ donation is against my religious beliefs.</td>
<td>5</td>
</tr>
<tr>
<td>If a family member signed a donor card, then I would approve the donation.</td>
<td>5</td>
</tr>
<tr>
<td>I am worried that a loved one’s body would be disfigured if their organs were donated.</td>
<td>5</td>
</tr>
<tr>
<td>People who receive organ transplants cannot live normal lives.</td>
<td>5</td>
</tr>
</tbody>
</table>

Cronbach’s coefficient α: all four sample years = 0.83; 1994, 0.83; 1995, 0.75; 1996, 0.88; 1997, 0.80.

Test-retest reliability was determined using the separate convenience samples of students: 18 undergraduates with 2-week measurement interval = 0.88; 61 undergraduates with 4-week measurement interval = 0.83; and 15 MBA students with 4-week measurement interval = 0.89.

* Statement sequence rotated to control for order bias.

Higher income persons are more likely to be organ donors. The Gallup survey (1993) found the likelihood to donate increases significantly with education and nonwhites are less likely than whites to want their organs donated. Non-Hispanic whites tend to have both higher donation rates and more favorable attitudes toward organ donation than do Blacks and Hispanics. This exacerbates the general organ shortage problem as some specific groups with a higher need for transplants also have a lower donation rate (Farrell and Greiner, 1993). Wheeler and Cheung (1996) also found that single Blacks and lower income Blacks are less willing to be donors after death.

In some instances, notwithstanding how they feel about donation, some people simply believe they are too old or cannot donate their organs due to medical reasons (Gallup, 1993). Having donated blood (Pessemier et al., 1977; Sanner, 1994a, 1994b) and knowing an organ transplant recipient are also thought to be related to willingness to donate (Horton and Horton, 1991).

The results of the analyses are mixed. While the groups do not differ by sex (p = 0.90), by race (p = 0.30), or by education (p = 0.31), they do differ significantly by age (p < 0.01) and by income (p < 0.001). The samples do not differ in the proportion of respondents who have donated blood (p = 0.70) or who personally know a transplant recipient (p = 0.50) (see Table 3).

Because the samples differ by age and income, DONATT was tested against the same demographic and experiential characteristics as were the sample groups (see Table 6). Recall that a higher DONATT score indicates a more favorable attitude toward organ donation. There is no difference in DONATT by sex (p = 0.58); but there is by age (p < 0.001), education (p < 0.001), income (p < 0.001, and race (p < 0.001). The age groups split right at age 60, with those 60 and over having a lower score than those under 60. Higher educational levels are associated with higher DONATT scores. Persons with high school/vo-tech or less education have lower scores than those with some college or a degree while those who have some graduate school or a graduate degree have higher scores than those with some college or an undergraduate degree. The income split occurs at $35,000. Those at or above $35,000 are more positive than those under $35,000. Whites and non-Black minorities have higher DONATT scores than Blacks. These findings conform with prior research (Wheeler and Cheung, 1996; Prottas, 1992).

Those who personally know a transplant recipient are more favorable than those who do not (p = 0.026). Those who have donated blood also have a more favorable attitude toward organ donation and transplantation than those who have not (p < 0.001). This also is confirmatory of prior research (Pessemier, 1977; Sanner, 1994a, 1994b; Horton and Horton, 1991).

The two characteristics that are significantly different both by sample year and by DONATT scores are age and income. Those over 60 years of age were progressively less represented in the samples. The level of income also shows a slight decline over the years of the study. These changes in income and in age distribution would likely mitigate against each other in

Table 2. Mean DONATT Scores by Year and ANOVA Results

<table>
<thead>
<tr>
<th>Year</th>
<th>Number</th>
<th>Mean</th>
<th>F</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1994</td>
<td>161</td>
<td>31.24</td>
<td>0.372</td>
<td>0.773</td>
</tr>
<tr>
<td>1995</td>
<td>126</td>
<td>31.45</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1996</td>
<td>142</td>
<td>31.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1997</td>
<td>141</td>
<td>31.52</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 3. Proportion of Participants Reporting That They Have/Have Not Signed an ODC by Year

<table>
<thead>
<tr>
<th>Signed an ODC?</th>
<th>1994 (n = 161)</th>
<th>1995 (n = 126)</th>
<th>1996 (n = 142)</th>
<th>1997 (n = 141)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>28%</td>
<td>37%</td>
<td>50%</td>
<td>44%</td>
</tr>
<tr>
<td>No</td>
<td>72%</td>
<td>63%</td>
<td>50%</td>
<td>56%</td>
</tr>
</tbody>
</table>

χ² significant at <0.01.
Table 4. Proportion of Participants Who Strongly Agree or Agree with the Statement “I would donate my organs after my death” and Who Report That They Have/Have Not Signed an ODC by Year

<table>
<thead>
<tr>
<th>Signed an ODC?</th>
<th>1994 (n = 109)</th>
<th>1995 (n = 86)</th>
<th>1996 (n = 99)</th>
<th>1997 (n = 91)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>39%</td>
<td>54%</td>
<td>67%</td>
<td>63%</td>
</tr>
<tr>
<td>No</td>
<td>61%</td>
<td>46%</td>
<td>33%</td>
<td>37%</td>
</tr>
</tbody>
</table>

χ² significant at <0.01.

Management Implications

This study indicates that the organ procurement and transplantation community must continue in its quest to understand what motivates individuals to become— or not to become— organ donors and to employ sophisticated marketing techniques to encourage donation. Special emphasis must be placed on the Black community in particular. While Blacks continue to demonstrate disproportionate need, they generally exhibit a less positive attitude toward donation and transplantation than do whites.

One approach to gaining insights about motivations may be to study blood donors. They are a readily identifiable group that is more positively disposed to the concept of organ donation and transplantation than persons who have never given blood. They have also displayed an intermediate behavior— more than a positive attitude, less than a signed ODC.

The change in age distribution should provide an upward bias and the change in income distribution should provide a downward bias.

The results of this study are mixed. DONATT scores are unchanged over the course of the four-year study but the proportion of respondents who had signed an ODC had actually risen significantly over the years. Something had to be at work to counteract the lack of enthusiasm for donation manifested by some members of the public. That “something” may have been the Ad Council/Coalition campaign. While there are differences among various demographic segments in their attitudes toward donation, the reality is that there are large numbers in all camps who have favorable attitudes. The need is to capitalize on those favorable attitudes.

While this gratifying upturn in signed ODCs has been contemporaneous with the Ad Council/Coalition campaign, it cannot be totally ascribed to it. Also contemporaneous with the campaign (perhaps due to the campaign) was news media attention concerning organ donation and transplantation. Such famous recipients as Larry Hagman, Mickey Mantle, and David Crosby, and such previously unknown donors as Nicholas Green (the young American boy whose parents donated his organs after he was killed by bandits in Italy) were in the news. This news should have helped galvanize public attention to the issue of organ recovery and donation. Parsing these effects is obviously difficult, but there can be little doubt the campaign was a major factor.

Limitations

Although probability samples were employed in every phase of the study, the study was limited to the metro area of Richmond, Virginia. This is the headquarters of UNOS, so there might have been an initial higher awareness of donation and transplantation. There is, however, no direct evidence of this. Projecting the findings beyond this area may be inappropriate.

Also, although the upturn in signed ODCs has been contemporaneous with the Ad Council/Coalition campaign, it should not be totally ascribed to it. As noted, several newsworthy events transpired which may have had an impact on the public’s perception of donation and transplantation. These events must also be allowed as having had an impact— whether positive or negative.

It should also be pointed out that the measure of action—
Table 6. Results of Tests Comparing DONATT Scores by Demographic and Other Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Test</th>
<th>Significance</th>
<th>Description of Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>ANOVA</td>
<td>&lt;0.001</td>
<td>Persons under 60 have higher scores than those 60 and older</td>
</tr>
<tr>
<td>Education</td>
<td>ANOVA</td>
<td>&lt;0.001</td>
<td>Persons with high school/vo-tech or less education have lower scores than those with some college or a degree, who have lower scores than those with some graduate school or a graduate degree</td>
</tr>
<tr>
<td>Income</td>
<td>ANOVA</td>
<td>&lt;0.001</td>
<td>Persons with household income less than $35,000 have lower scores than those with higher income</td>
</tr>
<tr>
<td>Race</td>
<td>ANOVA</td>
<td>&lt;0.001</td>
<td>Blacks have lower scores than other minorities and whites</td>
</tr>
<tr>
<td>Sex</td>
<td>t</td>
<td>0.580</td>
<td>Males and females do not differ</td>
</tr>
<tr>
<td>Blood Donor</td>
<td>t</td>
<td>&lt;0.001</td>
<td>Persons who have donated blood have higher scores than non-donors</td>
</tr>
<tr>
<td>Know Recipient</td>
<td>t</td>
<td>0.026</td>
<td>Persons who know a transplant recipient have higher scores than those who do not know a recipient</td>
</tr>
</tbody>
</table>

Groupings used for analysis: Age <30, 30–39, 40–49, 50–59, >59; Education: high school/vo-tech or less, some college, college degree, some graduate school or graduate degree; Income: <$35K, $35K–$64.9K, $65K–$95K, >$95K; Race: Black, other minority, white; Blood Donor: have donated, have not donated; Know Recipient: know an organ transplant recipient, do not know an organ transplant recipient.

Note: Duncan’s multiple range test (α = 0.05) was used in conjunction with ANOVA to test for differences between groups.

whether a respondent had signed an ODC—was a self-report and cannot be verified. Further, no attempt was made to determine if social desirability, or “yea-saying,” was at play in participants’ responses.

Appendix

Cadaveric Organ Procurement and Allocation in the United States

The National Organ Transplant Act (NOTA) of 1984 (as amended in 1988 and in 1990), the Uniform Anatomical Gift Act (UAGA), and the Sixth Omnibus Budget Reconciliation Act (SOBRA) provide the legal framework for organ donation in the United States. NOTA specifically outlawed the buying or selling of human organs and tissue and established the National Organ Procurement and Transplantation Network (OPTN) (Prattas, 1993; UNOS, 1997). Note that the use of financial incentives has been suggested by some as a means of increasing donations. For further information, see Altshuler and Evanisko (1992), Barnett et al. (1992), Cosse and Weisenberger (1997), and Kittur et al. (1991).

The UAGA explicitly authorized the voluntary gifting of body parts upon death and delineates a hierarchy of rules governing how the gift may be stipulated and who may commit the gift. The U.S. organ donation process is based on explicit consent. Under explicit consent, individuals (adults) decide if they wish to become organ donors. Typically commitment to be a donor is made by signing an organ donor card (ODC)—which may be one’s state driver’s permit. By law an individual’s wish to be a donor, as demonstrated by an executed ODC, is a binding authorization to remove the person’s organs after death regardless of the wishes of the individual’s family. In the absence of an ODC, the UAGA specifies which family members have a right to authorize a donation—generally, the spouse of an adult or the parents of a minor. SOBRA states that when there is no ODC, physicians and hospitals are required to present organ donation as an option to the families of patients judged to be dying or who have just died. This is referred to as required request (Farrell and Greiner, 1993).

The actual recovery and distribution is conducted by not-for-profit organ procurement organizations (OPOs) (Alexander et al., 1992). All OPOs and transplant hospitals are required by law to be OPTN members. Currently there are 54 independent and 12 transplant-center-affiliated OPOs in the United States. Upon notification by a hospital of a potential donor, OPO staff contact the families of potential donors to discuss the donation option, and if permission to recover organs is granted, they enter necessary donor data into the United Network for Organ Sharing (UNOS) computer system. UNOS is a private, non-profit organization that holds federal contracts to operate the OPTN and to maintain the U.S. Scientific Registry of Transplant Recipients. UNOS has specific policies regarding standards of membership, organ allocation, and data management. At this time the policies and standards are not enforceable by law and are considered voluntary guidance to OPTN members (UNOS, 1997).

UNOS provides the OPO with a priority listing of potential recipients. The first list generated is usually limited to patients in the OPO’s service area. If a suitable recipient is not found on that list, a regional list is generated, and finally a nationwide list is obtained. The OPO then contacts the OPOs in the areas where potential recipients are located. The donor’s OPO maintains the donor and coordinates organ recovery, preservation, and transportation. The recipients’ OPOs (one donor’s organs may go to a number of different recipients) arrange the transplant activities—line up the transplant teams and prepare the recipients for surgery. UNOS assists the recovery and transplantation teams with organ matching and transportation (Benenson, 1991) and oversees the process to ensure conformance with allocation rules, policies, and procedures.
In April 1998, the Department of Health and Human Services published the OPTN Rule requiring standardized criteria for listing patients on the waiting lists and for determining medical status (HHS 1998a). In addition, the rule eliminates the current practice of first searching for recipients within the recovering OPO’s service area. Further, it requires a nationwide search to find the person most in need of an organ(s). The rule was set to go into effect in July 1998 (see HHS, 1998b).

However, considerable opposition was expressed by members to Become a Potential Organ Donor. The rule was set to go into effect in July 1998 (see HHS, 1998b). Horton, Raymond L., and Horton, Patricia J.: A Model of Willingness to Become a Potential Organ Donor. Social Science Medicine 33, 9 (1991): 1048.


Nathan, Howard: Phase III Campaign for Organ and Tissue Donation. Coalition on Donation Memorandum to OPO Executive Directors (November 24, 1997).


