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The Combination of an Online Organ and Tissue Registry With a Public Education Campaign Can Increase the Number of Organs Available for Transplantation

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Abstract

Background—A persistent shortage of organs and inexhaustible waiting lists continue to result in many people dying while awaiting transplantation. On July 1, 2006, the California Department of Motor Vehicles joined forces with California's Online Organ and Tissue Registry and launched a campaign to increase donation rates. This campaign included intense public and media education. The efficacy of such a campaign on donor demographics has not been studied.

Methods—Retrospective analysis was conducted of organ donor referrals and donations from all southern California hospitals covered by a regional organ procurement agency. Organ donor demographics from 2 years before (pre-time: 2004–2005) and 2 years after (posttime: 2007–2008) were compared.

Results—Pretime included 6,112 referrals, 1,548 potential donors with 696 actual donors. Posttime included 7,119 referrals, 1,409 potential donors, and 699 actual donors. Consent for donation improved to 51.0% from 47.5% ($p = 0.064$), family decline decreased to 32.6% from 44.1% ($p < 0.0001$), and conversion rates improved to 49.6% from 45.0% ($p = 0.011$). Coroners also declined donation less frequently during posttime (1.8% vs. 0.6%, $p = 0.004$). Extended criteria donors improved to 9.5% from 3.8% ($p < 0.0001$), and donor after cardiac death improved to 3.0% from 1.4% ($p = 0.002$). A decrease in organs per donor was noted (3.57% vs. 3.14%, $p < 0.0001$) most likely because of the increase in extended criteria donors and donor after cardiac death.

Conclusions—Public and media education significantly improved organ donor demographics. Although this study compares only 2 years before with 2 years after the donation campaign, the results are extremely favorable. Therefore, a public donation campaign and an organ donor registry are effective promotions that could help increase the number of organs available for transplantation.

Keywords

Organ donor; Registry; Transplantation

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Because of ongoing advances in transplant immunology and surgical techniques, organ transplantation has become the standard of care for many patients with end-stage organ failure.¹ The success of transplantation and the growing demand for organs are exemplified by a perpetually burgeoning waiting list. Currently, 103,446 people are on this waiting list, and one new patient is added every 10 minutes.² Unfortunately, the growing demand for organ transplantation has not had a corresponding growth in organ availability. In 2008, only 27,963 transplants were performed, which is close to the 27,029 transplants performed in 2004.² More than 7,000 patients die per year while awaiting transplantation related to the lack of organs and lack of growth in transplant operations.³ This ongoing shortage of transplantable organs continues to be a national crisis. Despite aggressive efforts such as the Organ Donation Breakthrough Collaborative and the Organ Transplantation Breakthrough Collaborative,⁴ organ shortages continue to persist. The Institute of Medicine, in a 2006 report, offered a number of recommendations that could impact organ donation.⁵ Educating the public about organ donation and encouraging registration through donor cards, drivers' license, and donor registries were some of the actions recommended to help address the shortage of transplantable organs.

In July 2006, California's Online Organ and Tissue Registry, Donate Life California, joined forces with the Department of Motor Vehicles (DMV) in an effort to compel Californians to share their organ donation wishes by registering online.⁶ With this alliance, an individual could sign up with the registry when applying for a driver license or identity card through the California DMV or by signing up online. This campaign involved public and media education regarding the organ donor shortage. We set out to analyze whether this campaign had a beneficial effect on organ donor demographics in a catchment area covered by one of the California's organ procurement organizations (OPO). If improvement in organ donor demographics is documented, then similar campaigns can be replicated throughout the United States to improve the growing organ donor shortage.

PATIENTS AND METHODS

This is a retrospective study using the database from the southern California regional OPO, OneLegacy, which serves 14 transplant centers and more than 220 hospitals in the region.⁷ This OPO serves more than 18.3 million people in Los Angeles, Kern, Orange, Riverside, San Bernardino, Santa Barbara, and Ventura counties. The records of patients referred to the OPO for possible organ donation between the years 2004 and 2008 were reviewed. Data regarding the number of: referrals for organ donation, potential donors, actual donors, type of donor, family decline, organs recovered, and organs transplanted were recorded. The mechanism of injury (trauma vs. nontrauma), age, and sex of all donors was also recorded.

Types of donors include standard criteria donor (SCD), extended criteria donor (ECD), and donor after cardiac death (DCD). SCDs were declared legally brain dead by hospital criteria and were aged either younger than 50 years or 50–59 years with less than two of the following: chronic hypertension, stroke as the cause of death, or serum creatinine >1.5 mg/dL. ECDs were declared legally brain dead and were aged either older than 59 years or 50–59 years with two of the previously mentioned comorbidities. DCDs were patients with devastating neurologic injuries who donated organs after being declared dead by cardiac criteria following planned withdrawal of life-sustaining measures. Potential donors included medically suitable brain dead referrals plus the number of DCDs. Actual donors included all brain dead donors (SCD and ECD) and DCDs with at least one organ transplanted. The conversion rate was defined as the number of actual donors divided by the number of potential donors.

Comparisons of organ donor demographics were made between the time period before the registry campaign (2004–2005—pretime) and after (2007–2008—posttime). The year 2006 was excluded because the campaign started in July of that year. Statistical analysis was performed using the Student's *t* test for continuous variables and χ^2 with Yates correction for categorical variables. Differences were considered statistically significant if the *p* value was <0.05 . All statistical analysis were performed with SPSS 12.0 for Windows (SPSS, Chicago, IL), and statistical significance was set at $p < 0.05$. This study was determined to be exempt from institutional review board approval by the Institutional Review Board of the Cedars-Sinai Medical Center.

RESULTS

There were 6,112 referrals during the pretime period and 7,119 during the posttime period. A comparison between referral and donor demographics between the two time periods can be found in Table 1.

After institution of the online organ and tissue registry, referrals were more likely to be trauma patients, and more potential donors were ECDs and DCDs. Because of the large sample size, statistical differences in gender and the proportion of Hispanic referrals between the two time periods were noted; these difference were not part of the prestudy primary outcome measures, and they did not appear to be clinically relevant.

Notably, trends in consent rate, conversion rate, family decline rate, and coroner decline rate improved in the post-time. Consent for donation improved to 51.0% from 47.5% ($p = 0.064$), conversion rates improved to 49.6% from 45.0% ($p = 0.011$), family decline rate decreased to 32.6% from 44.1% ($p < 0.0001$), and coroners decline rate decreased to 1.8% from 0.6% ($p = 0.004$). A decrease in organs per donor was noted (3.57% vs. 3.14%, $p < 0.0001$) most likely because of the increase in ECD and DCD, which yield lower than expected organ number. Interestingly, there was a decrease in potential donors, in the posttime period, an unfortunate trend that seems to parallel the national decline in total number of potential donors.

DISCUSSION

Since the first kidney transplant in 1954, technological advancements in transplantation have advanced organ donation to a common and culturally accepted practice. However, despite improvements, a persistent shortage of organs and inexhaustible waiting lists continue to result in many people dying while awaiting transplantation. This shortage in the availability of transplantable organs continues to be a public health crisis in the United States with numerous public, private, and governmental agencies attempting to find programs to increase the recovery of organ donors. As a result of these efforts, there has been considerable growth in organ donors over the past 10 years. The Department of Health and Human Services has sponsored several initiatives, including the Organ Donation Breakthrough Collaborative and the Organ Transplantation Breakthrough Collaborative, which have resulted in increased deceased donors and available organs through identification and implementation of practices that are associated with related increases in organ donation.⁸ Despite these initiatives, the gap between organ supply and demand continues to grow. The Institute of Medicine has provided recommendations that may increase the supply of transplantable organs.⁵ In addition to quality improvement and research efforts, the Institute has called for increased organ donor registration and education to improve the opportunities for organ donation.

This study examined the effect of an online organ and tissue registry combined with a campaign of public education. Compared with the 2 years before the campaign, the 2 years after were associated with a significant increase in the consent rate and conversion rate, along with a significant decrease in the percentage of families who declined organ donation. There was a significant decrease in the number of organs recovered and transplanted per donor, which was most likely because of the significant increase in the number of ECD and DCD, which can lead to a decrease in available viable organs.

Educational campaigns involving the media, schools, churches, hospitals, and other institutions have been successfully performed in the past few years.⁹ In Europe, these campaigns resulted in a 53% increase in organ donation.⁹ In the United States, the National Minority Organ and Tissue Transplant Education Program was one of the most successful education programs created for increasing organ donation among minorities.¹⁰ Haustein and Sellers¹¹ demonstrated that organ donors are more likely to consider donation if they have viewed public information within the last 30 days or discussed the issue with family. These variables are interrelated and emphasize the need for frequent exposure to the topic of organ donation/transplantation.

A second strategy to increase the number of organ donors is to provide the public an easy way to sign up for donation. The California DMV and California's Online Organ and Tissue Registry joined forces and launched a campaign to increase donation rates. Partnering with the DMV to create an online registry helped ensure that every person had access to signing up for organ donation visiting the DMV.⁶ Historically, signing a donor card to obtain a "pink dot" on a driver's license served only as a symbol of the intent to donate; it did not place a name on an organ donor registry. This previous campaign did not guarantee that donor's intent would be performed. In July 2006, California closed this gap by launching an online organ registry that served as a living will for organ donors.¹² The Donate Life California Registry became a "first-person" registry in that next of kin are presented with documentation of registration but do not have the power to override the donation.

Along with the online registry, OneLegacy and JDI Communications started a three-tier approach for intense public and media education. The first tier consisted of media advocacy. OneLegacy used public services announcements, news conferences, and newspapers opinion-editorial page to produce awareness about organ donation to the public. The second tier involved community outreach in federal buildings, universities, and partnership with companies in the community. Tier three focused on reaching people without access in public libraries. OneLegacy partnered with libraries throughout the state to help people who may not have computers at home access the online registry.¹³ Siminoff et al.¹ identified the strongest predictor of refusal to donate to be the belief that the deceased would have not wanted to donate. Previous family discussions or a living will prevent this important source of uncertainty. The educational campaign promoted family discussion, whereas the online registry drafted a living will to better inform the donation wishes of the patient to the family. This communication is especially important in Hispanic Americans who are 60% less likely to donate their organs compared with non-Hispanic whites. As there is a paucity of literature to help explain the nature of decreased donation in Hispanic Americans, an additional focus of the current study targeted the Hispanic American Community, and this effort is ongoing.

Through the media advocacy and community-based efforts, the Donate Life California campaign registered 175,000 new individuals. These registered individuals represent the foundation for the future lives of organ donor recipients. The first time most individuals are formally asked to state their organ donation intention is at the time of receiving a driver's permit or license.¹⁴ However, once a person has obtained a license, returning to the DMV to change organ donor status is unlikely. The online donor registration acts as a tool for

individuals who change their minds about becoming an organ donor but do not want to return to the DMV. Therefore, it is imperative that we focus on education and tools to consent more organ donors.

Along with education, there are a number of ongoing initiatives and innovations as solutions to the organ shortage crisis. Two such solutions include presumed consent and financial incentives. According to presumed consent, an individual is an organ donor after his or her death unless the individual had documented objection during his or her lifetime. Although it would likely help donation rates, this concept unfortunately has not gained any traction in the United States and according to many, never will. The concept of financial incentives or “rewarding gifting” is gaining traction in the United States. There was a recent grant approved by the Department of Human Services to examine the role of paying living donors to cover the financial costs that are incurred as part of the donation process. These topics and a number of other initiatives are underway to help increase the number of available organs for transplantation.

There are a number of limitations to this study that should be considered. The retrospective design of the database limits the conclusions that can be made. For this reason, there is no way to analyze the direct effect of the educational campaign on organ donation rates. It is entirely possible that the increase in organ donor demographics was attributable to other factors. In addition, although the collaboratives were present throughout the time period studied, it is possible that they had a role in the favorable results seen. Finally, even though the conversion rate improved significantly in the second time period, it was still far below the 75% rate established by the organ donation collaborative.¹⁵ The cost implications are potentially prohibitive and must be considered. These costs included implementing enrollment in the DMV's system, which cost over \$1.1 million, and the attendant public education campaign, which was estimated to cost ~\$3 million. Despite these issues, this study represents one of the largest studies to date that addresses the beneficial effects of an online registry and educational campaign.

In conclusion, a public donation campaign and an organ donor registry are effective at increasing favorable organ donation trends. However, despite the significant increases in the consent and conversion rates, further work is necessary to help address the current organ shortage crisis. The studied educational campaign is easily replicable, and it should be considered as a method to favorably influence organ donation.

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TABLE 1

Comparison of Referrals and Outcomes Before and After Institution of the California Online Donor Registry and Education Campaign

	Before Registry, Pretime Period (2004–2005)	After Registry, Posttime Period (2007–2008)	<i>p</i>
Referrals	6,112	7,119	
Age (yr)	51 ± 20	52 ± 20	0.148
Gender (% male)	57	58	0.001
Trauma (%)	14	18	<0.001
Hispanic (%)	34	33	<0.001
Referral on the registry (%)	0	0.6 (n = 40)	<0.001
Potential donors	1,548	1,409	
Consent rate (%)	48	51	0.064
Family decline rate (%)	44	33	<0.001
Coroner decline rate (%)	1.8	0.6	0.004
Extended criteria donors (%)	4	10	<0.001
Donors after cardiac death (%)	1.4	3	0.002
Actual donors	696	699	
Conversion rate (%)	45	50	0.011
ORPD	3.6 ± 1.8	3.1 ± 1.9	<0.001
OTPD	3.1 ± 1.9	2.7 ± 2	<0.001

Conversion rate, actual donors/potential donors; ORPD, organs recovered per donor; OTPD, organs transplanted per donor.