Journal of Health Economics 49 (2016) 70–75

Contents lists available at ScienceDirect

Journal of Health Economics

journal homepage: www.elsevier.com/locate/econbase

Donor registries, first-person consent legislation, and the supply of deceased organ donors

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ARTICLE INFO

Article history:
Received 1 May 2015
Received in revised form 20 June 2016
Accepted 22 June 2016
Available online 27 June 2016

JEL classification:
I18
K32

Keywords:
Organ donation
Donor registry
First person consent
Policy evaluation
Difference-in-differences

ABSTRACT

In this paper, we exploit the varied timing in state adoption of organ donor registries and first-person consent (FPC) legislation to examine corresponding changes in the supply of deceased organ donors. Results indicate that the establishment of a state organ donor registry leads to an increase in donation rates of approximately 8%, while the adoption of FPC legislation has no effect on the supply of organ donors. These results reinforce the need to encourage individuals to communicate their donation preferences, either explicitly via a registry or by discussing them with family.

1. Introduction

Between 1988 and 2011, the number of individuals awaiting transplant of a vital organ grew by 650%, while the annual number of donors increased by only 140%. Over the same time span, the ratio of transplants performed to the size of the waiting list fell from 84% to 25% (OPTN, 2013; SRTR, 2012). Today's average transplant candidate has been waiting for an organ for more than two years, and the median wait time for kidney transplants is nearly four years[1] (SRTR, 2012). The growth of the transplant waiting list continues to outpace the marginal increase in organ donations year after year, while Organ Procurement Organization (OPO) estimates show recent declines in the number of identified potential deceased organ donors[2] (SRTR, 2012). On average, 18 individuals die each day while waiting for organ transplants (HRSA, 2012).

The shortage of donor organs is not a new problem. Since its inception in 1984, the Organ Procurement and Transplantation Network (OPTN) has been unable to secure enough organs to meet demand, and due to medical advances in recent years, mean survival times for those on the waiting list continue to increase (Klein et al., 2010; Siminoff et al., 1995; Traino and Siminoff, 2013). The U.S. has historically relied on altruistic donations, operating under what is known as informed consent whereby an individual must opt in and indicate their wish to donate before death. In the event that a potential donor's wishes are unknown, the next of kin is asked for consent. Contrary to the spirit of informed consent legislation, even when it can be verified that a potential donor has explicitly documented their desire to be an organ donor, it has long been the case that procurement professionals still request consent from the family of the decedent (Edinger, 1990; Siminoff and Lawrence, 2002). Several studies have reported an overall family refusal rate near 50%, while family members cite confusion or disbelief about brain death, concerns about burial and disfigurement, and a lack of knowledge of the decedent's donation preferences as the largest factors for refusing donation (Gortmaker et al., 1998; Siminoff and Lawrence, 2002; Siminoff et al., 1995).

In response to the continual shortage and persistently high family refusal rates, nearly all states have formed donor registries and passed legislation authorizing first-person consent (FPC) for organ donation (Chon et al., 2013). State donor registries provide a centralized method of recording potential donors' intent while FPC laws explicitly allow for donations from deceased donors to proceed when intent to donate can be confirmed (via donor card, driver's license designation, or state donor registry) without requiring transplant professionals to obtain permission from the next of kin. Moreover, FPC laws expressly forbid a third party from overriding the donor's

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[1] For those on the waiting list as of 2007, the most recent year data were available.

[2] Approximately 80% of all available organs come from deceased donors (after brain death or circulatory death) (OPTN, 2013).

http://dx.doi.org/10.1016/j.jhealeco.2016.06.009
0167-6296/

wishes unless they can produce confirmation of abrogation[3] (Mesich-Brant and Grossback, 2005; Traino and Siminoff, 2013).

Although nearly all states have adopted both organ donor registries and passed FPC legislation with the aim of increasing donation rates, the effect of these interventions on the supply of deceased donor organs remains uncertain (Caplan et al., 1991; Sheehy et al., 2003). Despite heightened concern over the growing gap between the demand and supply of transplantable organs in the U.S., relatively few studies have analyzed recent attempts to increase donation rates and those that do tend to focus on incentives for living donors (Bilgel and Galle, 2015; Lacetera et al., 2014; Venkataramani et al., 2012). While the share of transplanted organs from living donors has increased, over the past two decades deceased organ donations far outweighed the number of transplants from living donors (UNOS, 2013). Our study represents the first effort to evaluate the impact of the two primary interventions to increase deceased organ donations in the U.S. The efficacy of such policies, which often operate through different causal pathways, remains an open question. For example, donor registries primarily affect donation rates by clarifying the intent of the potential donor while FPC legislation lowers the implicit cost of donation by limiting familial interference in the donation process (Ojo et al., 2004; Traino and Siminoff, 2013). Identifying the relative influence of each mechanism on donation rates is an important factor in the establishment of effective public policy to address the shortage of organs available for donation.

In this paper, we exploit variation in the timing of state adoption of donor registries and FPC legislation to estimate the effects of both interventions on the supply of deceased organ donors. Using data on the number of deceased organ donors by state from 1988–2006, we examine changes in the supply of deceased and brain-dead organ donors in response to both donor registry adoption and FPC enactment, the efficacy of which have yet to be studied. Our results indicate that state adoption of an organ donor registry is associated with an increase in donation rates on the order of 8.1–9.5% while we find no individual effect of FPC laws. These findings are robust to various model specifications and definitions of the donor rate and suggest that the establishment of state organ donor registries, and not the passage of FPC legislation, led to sizeable increases in the supply of deceased organ donors. Coupled with typically low family consent rates when the wishes of the donor are unknown, these results reinforce the need for actions that encourage more individuals to communicate their donation preferences, either explicitly via a registry or by discussing them with family.

2. Background

2.1. Organ donor registries

In the late 1980s and early 1990s, states began establishing organ donor registries in order to facilitate the time-sensitive procedure of organ procurement from deceased donors. Commonly, individuals express their intent to donate by adding their name to their state registry at a Department of Motor Vehicles (DMV) location or through online enrollment (Punch et al., 2007). Though the first state donor registry was established in 1988 following the 1987 passage of the first Uniform Anatomical Gift Act (UAGA), not until 2010 did an organ donor registry exist in all 50 U.S. states.

There are two primary pathways through which organ donor registries plausibly affect donation rates: by simplifying identification of potential donors and by signaling donor intent. Prior to the establishment of state donor registries, donors were typically identified through donor cards that were often unavailable at the time of procurement (Sung et al., 2008). Additionally, families are far less likely to provide consent when a potential donor's preferences are ambiguous (Siminoff and Lawrence, 2002; Siminoff et al., 1995). Signaling intent by registering as an organ donor reduces ambiguity following death and has been shown to lead to familial consent rates as high as 95–100% when the decedent's intent to donate was known (Ojo et al., 2004). While anecdotal evidence suggests that donor registries may be an effective method of increasing donation rates, actual evidence of their efficacy is sparse (Caplan et al., 1991; Sung et al., 2008).

2.2. First person consent legislation

In an effort to increase uniformity in the donation process across states, the UAGA of 2006 included a first-person consent provision preventing any family member or otherwise responsible party from revoking an anatomical gift made by a potential donor prior to death (ULC, 2006). The Act allows for consent to be expressed in several forms including donor status designation on a driver's license or ID card, a donor card, or via compliant donor registries.

Prior to the widespread adoption of the 2006 UAGA, twelve states had enacted FPC of their own accord (see Appendix Table A1).[4] Seven of these states passed FPC legislation, at the same time they implemented a legally binding donor registry. Florida, Illinois, and New Mexico had existing donor registries when they passed FPC, while Minnesota and Virginia did not implement a registry until after FPC was already in place (UNOS, 2010).

3. Data

We obtained data on the number of deceased adult donors by state from 1988 through 2006 from the OPTN. The United Network for Organ Sharing (UNOS) provided years of adoption of state-level FPC legislation. We compiled the years of enactment for state organ donor registries from Donate Life America's annual donor designation report cards. Appendix Table A1 lists years of registry establishment and the year FPC legislation became effective by state.

State-level health expenditures were retrieved from the Centers for Medicare and Medicaid services. Demographic data including age, race, and educational achievement by state were compiled using the Current Population Survey's outgoing rotation group files. Data on population density and adult population within each state, as well as median income, were retrieved from the U.S. Census Bureau and the U.S. Statistical Abstract. Income and healthcare expenditures were adjusted for inflation and are reported in 2012 dollars.

In order to control for changes in resource allocation or increased efforts to promote awareness of donation associated with registry or FPC adoption, we obtained data on OPO annual operating revenues from the National Center for Charitable Statistics (NCCS). To generate estimates of per capita OPO operating revenue, we began by collecting annual reported total revenue from the IRS Form 990 for 50 of the 58 OPOs currently in operation.[5] For OPOs operating exclusively within a particular state, we used annual state population estimates from the Census Bureau as the denominator to construct our per capita revenue measure. In cases where OPOs

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[3] Although, some states require only a verbal expression of revocation in the presence of two individuals (one of whom is disinterested); written documentation is not always necessary (ULC, 2006).

[4] The first states to pass the 2006 UAGA did so in 2007; it was approved by the NCCUSL for promulgation in July 2006.

[5] Eight OPOs are hospital-based and therefore do not file a separate IRS Form 990. This prevents us from calculating annual revenue estimates for these OPOs. Consequently, we assign each of these hospital-based OPOs the average annual per capita revenue calculated from the remaining 50 OPOs for which we have valid revenue measures. We have conducted each of the following analyses dropping any states that are served by a hospital-based OPO and the results are largely unchanged.