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Increasing Organ Donations in Maryland: An Interrupted Time Series Analysis

Laura A. Gerlach
Walden University

Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Laura A. Gerlach

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Review Committee
Dr. Victor Ferreros, Committee Chairperson,
Public Policy and Administration Faculty

Dr. Boris Bruk, Committee Member,
Public Policy and Administration Faculty

Dr. Lydia Forsythe, University Reviewer,
Public Policy and Administration Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
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Abstract

Impact of Maryland's Efforts to Increase Donor Registration Rates

Laura A. Gerlach

MS, Marymount University, 1995

BS, James Madison University, 1980

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Public Policy

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Abstract

The state of Maryland has been unsuccessful in achieving its goal of registering its entire population as organ donors. The registered donor participation rate has remained static, and organ supply is insufficient to meet demand. The purpose of this correlational study was to understand if efforts in the state of Maryland to increase donor registration rates were successful. The donor registration program allowed registered donors to opt out of the heart icon program to overcome the myths of the effect of the heart icon on a person's driver's license. The research question for this study examined the effectiveness of this program by allowing registered organ donors to remain anonymous. The theoretical foundation of this study was the theory of planned behavior. The research methods utilized included regression displacement, interrupted time series analysis, auto correlation analysis, and Box-Jenkins Autoregressive Integrated Moving Average Model (ARIMA). Data were collected from the Motor Vehicle Administration of Maryland and the Division of Motor Vehicles of Virginia. Study findings suggested that offering the option to remain anonymous and registering to be an organ donor with no heart icon on the driver's license did not encourage more people to register as organ donors. Parameter estimates from an Arima autoregression analysis did suggest that the impact of the removal of the heart icon may have a delayed impact, although data availability limited attempts at further investigation. These findings have implications for positive social change because by studying the effect of providing new options for organ donation and registration, it may be possible to increase the likelihood that more people will register to become donors. In the end, more organ donors equal more lives saved.

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Dedication

I dedicate this work to my husband, Bryce M. Gerlach, Jr.; the man of my dreams, my partner and friend, the one I adore and admire. His love for our Lord and his dedication our family are the things I love most about him. But without his unwavering support, and his ability to stay positive even when things look bleak, I could never have completed this task. The humility he exhibits and how he gently leads the way is a daily example to me. His wisdom always leaves me speechless. I could never have accomplished much in my life without him as my partner; cheering me on. I dedicate this work to him as it is as much his as it is mine, as I couldn't even have stepped on to this path without his unwavering love for me.

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Chapter 1: Introduction to the Study

Organ donation is a part of health care in the United States. The goal of organ donation is to save lives. There are two possible ways to become an organ donor. Most donations occur after death, but some members of the population become a living donor by donating a kidney or a portion of their liver or lung. This life-saving surgery has impacted thousands; yet, thousands remain on the waiting list to receive an organ. Transplantation is available to all. However, in the United States, more people need to register to become donors upon their death. The lack of education and myths that surround donation have proven to be obstacles in registering more people as donors.

Background of the Study

Organ donation began in the United States in the 1970s. The Uniform Anatomical Gift Act (1968) established laws to support state organ donation, and it developed the first organ donor cards and methods for registering as a donor. The law also established a centralized registry for organ matching and placement, while outlawing the sale of human organs. In 1984, the United States Congress passed the National Organ Transplant Act. The goal of this act was to monitor the ethical issues around donation and put a focus on organ shortages in the nation. The first computerized database for people waiting to receive organs was developed in 1977 (United Network for Organ Sharing, 2017). Since that time, there has been a nationwide effort to increase the number of people who are registered as organ donors.

Currently, there are 117,990 people waiting for the life-saving gift of an organ (United Network for Organ Sharing, 2017). The current organ supply is insufficient to meet demand (O'Carroll, Dryden, Hamilton-Barclay, & Ferguson, 2011).

Problem Statement

The state of Maryland has been unsuccessful in achieving its goal of registering all of its population as organ donors. The state currently has 59% of its population registered as donors. In comparison, Virginia’s organ registration rate is 61%. Maryland lags behind many states in organ donor registration. The national registered donors’ participation rate over the past 20 years has remained static; although, the number of people waiting for a life-saving organ has increased by 10% (Cameron et al., 2013). The organ supply is insufficient to meet demand (O’Carroll et al., 2011). Despite the wealth of data on registration rates, there is little literature on viable, alternative ways to entice individuals to register as an organ donor. As a result, thousands of Maryland residents are currently waiting for an organ, and 22 people die daily waiting for an organ (van Andel, Tybur, & Van Lange, 2016). Despite many educational efforts, nationally, more than 48% of the population remains unregistered to be an organ donor. To address the problem, Maryland instituted a program with the Motor Vehicle Administration (MVA) to increase donor registration rates. In this study, the literature of organ donor registration was expanded and examined new and untested options in the state of Maryland to determine if there were ways to increase registration rates with Marylanders.

Purpose of the Study

The purpose of this study was to understand if efforts by the state of Maryland to provide registered donors an option of remaining anonymous increased donor registration rates. Some individuals do not trust doctors or the medical community (Hyde, Wihardjo, & White, 2012). The Maryland MVA became aware of a myth regarding registration and considered that this myth may prevent individuals from becoming registered organ donors. Some members of the population believed that if doctors saw that an individual was an organ donor on his or her driver's license, the doctor would not work hard to save a life in an effort to get the organs for other patients. In an effort to overcome this myth, Maryland designed a program allowing registered donors to opt out of the heart icon program on their driver's license. However, scholars have not determined if the opt-out option will lead to increased donor registration. No other state in this country has offered the option of allowing registered donors to register but opt out of the heart icon program, allowing them to remain anonymous. In order to understand the impact of this program, a state without this program was examined to provide data to understand if providing this option had value. The state of Virginia was chosen as it had similar demographics and populations as the state of Maryland. It is important to register more donors to increase the availability of transplantable organs for those waiting for the life-saving gift and to prevent a difficult family decision by encouraging people to make the choice to become a donor before their death.

Significance of the Study

In this research, there is an attempt to fil a gap in understanding if allowing registrants to remain anonymous will increase donor registration rates. Data was examined to learn if having the option to opt out of the heart icon program increased donor registration numbers. According to Rodrigue et al. (2012), 97% of all people who register as organ donors do so at their local Division of Motor Vehicles. Because of the high volume of people who visit the MVA in the state of Maryland, this study provided the ability to gather data regarding this issue.

Nature of the Study

This study was quantitative in approach. Quantitative researchers examine patterns, as expressed in numbers (Rudestam & Newton, 2015). This study was a time series design using regression displacement design in the beginning. A comparison of time series data on organ donations for Maryland and Virginia over a 2-year period, including the policy intervention, was conducted. Virginia was the control group, and the periods before and after the intervention in Maryland were compared. Donor registration rates were examined before the program and then examined after the program was implemented to compare those who registered to become organ donors and did not opt out of the heart icon program for a 1-year period against the same period when opting out was not an option. These were the two main time periods. This pattern should be reflected in registration rates. In this study, the combined differences between groups of registered organ donors were shown. The focus was to measure these data, while controlling for any potential errors (Rudestam & Newton, 2015). This methodology allowed me to include variables that can be measured.

Research Questions and Hypotheses

Two primary research questions (RQ) and two hypotheses were included in this study.

RQ$_1$: To what extent does the ability of registered organ donors to opt out of the heart icon program, increase registration rates?

H_{01}: Allowing Maryland registered organ donors to opt out of the heart icon program will increase organ donor registration rates.

$H_1$1: Allowing Maryland registered organ donors to opt out of the heart icon program will not increase organ donor registration rates.

RQ$_2$: What age demographic is holding down registration rates?

H_O2: Specific age ranges can be identified as those opting to not registered as donors, and thus hold down the registration rates.

$H_1$2: No specific age ranges could be identified as those opting to not register as donor, and thus hold down the registration rates.

Theoretical Framework

The theoretical basis for this study was the theory of planned behavior. The theory of planned behavior is a useful model of health behavior and has been employed to explain patterns of organ donation behavior. The theory considers the impact of attitude, subjective norm and perceived behavioral control on behavior. Attitude, norm and behavioral control are determined by normative, behavioral and control beliefs. The theory of planned behavior maintains that a major determinant of behavior is a person's intent which is influenced by attitudes and norms. It has been applied to organ donation behavior in this research. Many studies regarding organ donation have looked at attitudes regarding donation. Religion, role misconceptions, age, education, ethnic beliefs are some of the factors that are discussed in this chapter that serve to better understand the context of donation behavior within the theory of planned behavior. Using a theory of health behavior when looking at organ donation can help to explain the contributing factors to making a decision and can tell more about the relationships between these factors. The Theory of Planned Behavior offers the opportunity to examine a person's attitude and perceived behavioral control of a behavior. Their attitude, no matter positive or negative is determined by the perceived consequences of the behavior. The theory of planned behavior recognizes that intention alone does not always predict behavior.

Assumptions

In this study, it was assumed that more research was needed to better understand how to register more people as organ donors. It was assumed that allowing registered donors to opt out of the heart icon program, and to become anonymous, would have a significant impact on registration. It was assumed that the data provided and the calculations that followed aligned with the research and presented a clear picture of the outcome. In addition, the possibility of an age effect will be investigated to determine if there was a certain age demographic that was affecting the registration numbers. It is also assumed that the data collected from the DMV in both the states of Virginia and Maryland were accurate.

Scope and Delimitations

The program allowing registered donors to remain anonymous began in October 2015; therefore, registration rates 1 year prior to this program were examined and compares them to a year while the program was in place. The scope of the study was limited to the calendar year of October 2014 through September 2015 for historical data, and October 2015 through September 2016 when the option to opt out of the heart icon program became available. Insights gleaned from this study allowed a greater understanding of determining if allowing registered donors to remain anonymous will have an impact on donor registration.

Limitations

The length of the time series employed in this study spans thirty months. A more extensive time series would have been desirable. The agency employees in both states felt the effort required to gather more data simply was too resource and time intensive. more extensive time series may eventually be needed to better understand the data.

Definitions

Donate Life: Donate Life is a nonprofit organization that has state chapters that support organ donation and work to increase the number of registered donors. They work in partnership with the DMVs nationwide.

Living donation: The process by which a person who is alive who donates a kidney or a portion of his or her liver or lung to another person. Hospitals actively support living donation and encourage loved ones of those who are ill to consider participating.

Organ donor: This is an exact term for any person who agrees upon his or her death to donate his or her organs. It can also refer to someone who dies, and his or her living next-of-kin chooses to have him or her become a donor of his or her organs. This donation can also be to someone who is living, and it could be applied to research.

Organ donor registration: This term refers to the active participation of persons who sign up as an organ donor upon their death by many ways possible. They can choose to sign up at their local DMV, or they can sign up on various websites. In addition, the organ donation community holds events with in-person opportunities to register. The process of registering is accepting yes.

Organ procurement organization (OPO): OPO is a nonprofit organization that partners with hospitals when there are potential donors. There are 58 OPOs nationwide who play an active role in organ donation. They are also active in increasing the number of registered donors nationwide.

Organ Procurement Transplant Network (OPTN): The OPTN operates under contract with the United States Department of Health and Human Services, and they are managed by UNOS. They are a resource for data, education, and the current numbers of those waiting to receive an organ.

United Network of Organ Sharing (UNOS): UNOS is a nonprofit, private organization that manages the waiting list for all those waiting to receive the life-saving gift of an organ, and they also participate in matching donors to recipients. They are the national organ transplant system.

Summary

In Chapter 1, an introduction to this study was provided, presenting the overview of organ donation and the challenge to increase the number of registered donors. Statistical data were provided that established the foundational parts of this study, which will bring to light the need for more donors to meet the need of the ever-growing list of those waiting for an organ. The theoretical framework provided the basis to understanding if allowing registered donors to remain anonymous will increase registration rates by supporting the assumption that the myth discourages organ donation. In addition, it was also useful to determine if the ages of those who register to donate reflect any specific age ranges.

Chapter 2, consists of a review of the body of literature on the subject of organ donation, previous research methods to increase registration rates, and conceptual frameworks used to better understand the behavior of organ donor registration in the context of the theory of planned behavior. It is hoped that it will improve insight on ways to increase registration rates, either by allowing anonymity or focusing education of a specific age group. In Chapter 3, provides descriptions of the choices of methods and the rationale in this study, including design, data collection, analysis, and impact of that analysis. In Chapter 4, the results of this study will be outlined. In Chapter 5, all key findings will be summarized and will include any recommendations and discussion points, as well as possible future research opportunities.

Chapter 2: Literature Review

Introduction

The state of Maryland has been unsuccessful in achieving its goal of registering all of its population as organ donors. The state currently has 59% of its population registered as donors. The registered donors' participation rate has remained static, although the number of people waiting for a lifesaving organ has increased by 10%. The organ supply is insufficient to meet demand (O'Carroll et al., 2011). Despite the wealth of data on registration rates, there is little literature on viable, alternative ways to entice individuals to register as an organ donor. As a result, thousands of Maryland residents are waiting for an organ, and 22 people die daily waiting for an organ (van Andel et al., 2016). Despite educational efforts around the country, more than 45% of the population remain unregistered to be an organ donor. To address the problem, Maryland instituted a program with the MVA, allowing registered donors to remain anonymous. In this study, the literature of organ donor registration is examined and as well as new options in the state of Maryland to determine if there are possible stimulants to increase registration rates with Marylanders.

The purpose of this study was to understand if efforts to increase donor registration rates were successful. The program allowed registered donors to opt out of the heart icon program in an effort to overcome the myths of the impact of the heart icon on a person's driver's license. Many do not trust doctors or the medical community (Hyde et al., 2012). No other state has offered the option of allowing registered donors to register but opt out of the heart icon program, allowing them to remain anonymous. It is important to register more donors to increase the availability of transplantable organs for those waiting for the life-saving gift and to prevent a difficult family decision by encouraging people to make the choice to become a donor before their death.

Literature Search Strategy

In a search for literature, articles were found from several electronic databases, including BioMedCentral, CINAHL & MEDLINE Simultaneous Search, CINAHL Plus with Full Text, MEDLINE with Full Text, ProQuest Central, ProQuest Health & Medical Collection, and SAGE Journals. The search terms used in conducting this literature search included the following: *organ donor, donor registration, organ donor registration, heart icon, organ donation, tissue donation, organ donation DMV, organ registration DMV, organ donor myths, organ donor concerns, organ donor attitudes, organ donor acceptability, organ donor resistance, informed consent, knowledge of organ donation, donor families, organ donor empathy, organ donor life orientation, deceased organ donation, organ donor campaign, state registry, organ donor legislation, anonymous donation, heart symbol organ donation, transplantation, donor conversion, National Organ Transplant Act of 1984, nondonors, organ donor's religion, organ donation barriers, organ donation saving lives, and organ donor misconceptions*.

Theoretical Foundation

The theoretical model that was used was the theory of planned behavior. The theory of planned behavior is a useful model of health behavior and has been employed to explain patterns of organ donation behavior. Many studies regarding organ donation have looked at attitudes regarding donation. Religion, role misconceptions, age, education, ethnic beliefs are some of the factors research has learning that effect organ donation. In addition, many myths surround organ donation. This research looks to understand if the myth concerning the distrust of the medical profession can be overcome. The myth states that if a doctor sees the heart icon on your driver's license, he/she will not work to save your life. If Maryland offering the option of remaining anonymous and allowing registered donors to not have the heart icon on their driver's license, will that overcome this myth and encourage more donor registration. The Theory of Planned Behavior offers the opportunity to examine a person's attitude and perceived behavioral control of a behavior. This study will look to see if a person's attitude about organ donation can be affected by the option of remaining anonymous.

Design of the Study

This was an observational study. In this study, there was no manipulation of the intervention. The pre/post design included comparing the same group before and after the change of policy. It was assumed that the outcome will not have changed minus the policy. The design included two groups: the state of Maryland and the state of Virginia. Virginia functioned as the control group. Only Maryland had been exposed to the policy change. In this interrupted time series study, there was a comparison of longitudinal trends before and after the policy change. The data used were provided by the state of Maryland MVA and the state of Virginia DMV. The data were stable and representative of 2 years (October 2015 through October 2016), with historical data from October 2014 through October 2015.

Literature Review Related to Key Variables and Concepts

Organ Donor Registration

Many researchers encourage organ donation. Scholars have explored why people do or do not register to be organ and tissue donors. Salim et al. (2015) examined the positive impact of kiosks in primary care clinics as a way to increase registration. In addition, body integrity issues reduced the likelihood of registration (Shepard & O’Carroll, 2014). Minorities are also concerned with body integrity (Dunleavy, 2013). An immediate, complete registration opportunity is unlikely to increase registration rates without additional support and effort (Siegel et al., 2016). The higher the social economic status, the more likely the individual is to be a donor (Reibel, Olmo, Andrada, & Koertzen, 2016). More people will register as donors if they are verbally asked (Hajhosseini, Stewatt, Tan, Busque, & Melcher, 2013). The state efforts to increase donor registration can be effective if educational materials are provided (Vertanous et al., 2016). Although the United States is an opt-in donation program where a person must opt in as a donor, scholars have also examined opt-out programs. Willis and Quigley (2014) indicated that an opt-out program would increase registration rates, but it has not been demonstrated as having an effect. Opt-out programs can work in coordination with presumed consent (Whyte, Selinger, Caplan, & Sadowski, 2012). Next-of-kin relationships have an influence on registration rates (Ahmad & Iftikhar, 2016).

Minorities and Registration

Minorities are underrepresented in donor registration, and researchers have attempted to learn why minorities do not register as organ donors. African Americans may perceive that chronic medical conditions, including hypertension and diabetes, would prevent them from being able to donate, which is a false assumption (DuBay et al., 2014). Intervention can lead to increased registrations among African Americans (Rodrigue et al., 2012). In addition, family and friends in minority groups are not supportive of registration (DuBay et al., 2014). Hispanic Americans are also an underrepresented population in organ donation registration. Hispanic Americans have a much lower donation rate than non-Hispanics. Many Hispanics believe that donation is forbidden in the Catholic religion (Salim et al., 2012). Asian Americans record a much lower registration as well (Achcmedia.com, 2014). Asian American adolescents are willing to donate, but communication with family members about this decision is important (Trompeta et al., 2012). Minorities are also noted as mistrusting the medical system, and this mistrust extends to organ donation (Quick, LaVoie, Scott, Bosch, & Morgan, 2012). The major reasons why African Americans are reluctant to register include the following: awareness of the problem, mistrust of those in medicine, fear of death, discrimination, and religious beliefs (Brown, 2012). Although 13% of the population is considered African American, they represent more than 29% of those on the wait list for organs (Dunleavy, 2013). Understanding cultural beliefs can have a positive impact on messages to minorities (Jernigan et al., 2013). When the families are asked to donate their loved family member’s organs, they are likely to decline. Through education, most populations can alter their views.

The Internet and Organ Donation

Over the past decade, as the Internet has become more commonplace, scholars have explored if using the Internet could increase donor registration rates. In 2012, Facebook set up a platform for members to specify on their profile if they are an organ donor. In addition, educational links were added. Cameron et al. (2013) found that a small portion of users had a positive image of organ donation. In addition, Hitt, Gidley, Smith, and Liang (2014) conducted a study to learn if providing an online competition between colleges to score the most points to register as donors would increase donation registration. Hitt et al. reported an incremental increase in registrations, as more social media was added. An additional college challenge was studied to learn if social media ads generated registrations (Smith et al., 2016). Although Stefanone, Anker. Evans, and Feeley (2012) failed to increase the number of people who registered their donation intentions, much was learned about how to use websites to market organ donation. Social media can bolster organ registration rates (Feely & Kruegler, 2015).

College Students and Registration

Britt, Britt, and Anderson (2015) examined rural college students to learn if the willingness to become an organ donor could be predicted by moral norms. In addition, researchers explored if communication about donation could move college students from awareness to behavior (Peltier, D’Alessandro, Dahl, & Feeley, 2012). Positive messaging impacted willingness to register as a donor (van Andel et al., 2016). In a study of 18-

year-old students, students indicated that they did not think about donation (Quick et al., 2012). Students would only support donation if it benefited society; thus, more work should be done to educate students to enhance registration and acceptance of organ donation (Peltier et al., 2012). There is a need to enhance the acceptance of registration for organ donation with college students by communicating to move them from awareness to registration behavior (Peltier et al., 2012).

Organ Donation Policy Issues

Chatterjee, Venkataramani, Vijayan, Wellen and Martin (2015) examined the effects of state policies provided incentives for people to register to donate, and they learned that these policies had no significant impact. In another study, state policies had little impact on organ donation registration rates (Matas & Hays, 2015). Policies to encourage registration as a donor had no effect on donation and transplantation (Chatterjee et al., 2015).

The Division of Motor Vehicles

Ninety-seven percent of all those that register as organ donors do so at their local DMV (Rodrigue et al., 2012). Many studies have been done to learn how to positively impact registration rates at the DMV. Siegel et al. (2016) examined if negative feelings at the DMV translated to negative feelings about donation. The state of West Virginia launched a program to learn if web-based training of the staff at the DMV would improve registration rates and found that the results were positive (Degenholtz, Resnick, Tang, Razdan, & Enos, 2015). The state of Massachusetts performed studies to learn if video messaging at the DMV would increase donor registration and found that it did not have an impact on registration rates (Rodrigue, Fleishman, Fitzpatrick, & Boger, 2015). Rodrigue, Fleishman, Vishnevsky, Fitzpatrick, and Boger (2014) studied the impact of video messaging and how it equated to behavioral intent to register and found that 1-minute videos can have a positive impact on organ donor registration. In New York State, Feeley, Reynolds-Tylus, Anker, and Evan (2014) explored the reasons why people did not sign up as an organ donor. In the state of Florida, Rodrigue et al. (2012) studied the effectiveness of a statewide intervention with the DMV to increase registration rates. Although asking for money to support organ donation relieved moral pressure on the applicant, it did not encourage more registrations (Hajhosseini et al., 2013).

Additional Research Topics Considered

Myths and misconceptions impede donor registration. Misconceptions about allocation and eligibility are widespread (Merola et al., 2016). One myth is that doctors will not save the life of a registered donor (Shepherd & O'Carroll, 2014). Another myth is that rich and famous people go to the top of the waiting list (DonateLifeMaryland.org, 2017). In addition, there are concerns that rich people can buy organs (Quick et al., 2012). These myths reduce the number of registered donors. People's attitudes play a role in their decision to become a donor. The most common reason cited for not registering as a donor was religious views; although, most religions around the world support organ donation (Salim et al., 2012). Religion is the most often noted barrier to registration to organ donation (Shepherd & O'Carroll, 2014). Although religious leaders are noted as supporting organ donation, religion continues to be a reason not to register (Irving et al., 2014). Confusion about religious support, family support, and the negative beliefs impact organ registration decisions. Concerns about the black market for organs is also a concern (Hyde et al., 2012).

Family interactions can impact donor registration rates. Families with little knowledge about donation prior to the pending death of a loved one are more apt to decline donation (Marck et al., 2016). Education can improve registration rates. A family's wishes and ensuring that their wishes align with the donor's wishes at the time of death, can create a challenge to donation (Toews & Caulfield, 2016). A lack of family support for donation reduces the likelihood of organ donation (Salim et al., 2012). Family influence can be positive, if they have been provided with knowledge about transplantation and donation (Walker, Broderick, & Sque, 2013). Families should discuss these wishes when registration is being considered. When family members know they have saved a life, they have no regrets about donation, while others may feel regret when opting not to donate (Marck et al., 2016). Inadequate support from family members adds to the feeling of being overwhelmed by the decision whether or not to donate organs (deGroot et al., 2016). There is a need for more education and support around the decision to donate.

Marketing programs can impact donor registration. In Iowa, residents were receptive to direct mail campaigns to increase donor registration (Quick, Reynolds-Tylus, Fico, & Feeley, 2016). In Illinois, an invitation via the U.S. mail resulted in increased registration rates (Quick, LaVoie, Morgan, & Bosch, 2015). In a study with college students, Chien and Chang (2015) found that giving positive messaging promoted registration rates, regardless of the graphics used in the marketing materials. Cues to action have a positive impact on registration rates (King, Williams, Harrison, Morgan, & Havermahl, 2012). Mass media campaigns can serve as a means for educating the public about organ donation (Rady, McGregor, & Verheijde, 2012). Marketing results can be difficult to analyze and quantify; however, organ donor campaigns can produce positive results in registration (Thomas, Scott, Forsythe, & Marson, 2015).

Summary and Conclusions

There is a need to learn new ways to encourage more people to become organ donors. Organ donation is a health concern in the United States (Gilligan, Sanson-Fisher, & Turon, 2012). The waiting list for organs grows daily. Efforts such as those put forward by the state of Maryland will provide more information on how to increase registration rates.

In the literature review, research was examined on the topics considered in attempting to increase donor registration. Family dynamics, ethics, minorities, religion, registration rates, registries, the DMV, and various age groups studied expanded the understanding of attempts to not only understand why the registration numbers are low, but also what techniques might work to increase donor registration rates. There is an association between the anticipatory effect and a person’s intentions to participate in organ donation behaviors (Rocheleau, 2013). Reciprocity is supported by many scholars (Chandler, Burkell, & Shemie, 2012). Many community members consider altruistic influences when considering organ donation. Altruism should be a motivator for organ donation (Irving et al., 2014). With the Gallup Poll organization reporting that 95% of all people in the United States supporting organ donation, there is a need to increase registration rates (as cited in Feeley, Reynolds-Tylus, Anker, & Evans, 2014).

Chapter 3 provides a detailed explanation of the research methods used in this study.

Chapter 3: Research Method

Introduction

Organ transplantation is a life-saving medical innovation. The miracle of organ transplantation saves or improves the lives of thousands of people each year. The miracle makers are the donors who give the gift of life. Organ donors are needed to save lives. In the United States, the challenge continues to register more of the population as organ donors upon their death. Many do not register, due to lack of education, belief in myths, and the consideration of mortality. Much research has been done to learn how to best increase registration rates; however, the wait list for potential recipients continues to grow, as organ donor registration rates remain static. In this study, it was examined if a program initiated by the state of Maryland, in cooperation with the MVA, increased registration rates. In this quantitative study, the relationship between the ability to remain anonymous in registering to become a donor and an increase in registration rates was examined.

In Chapter 3, describes the research problem, sampling strategy, design rationale, questions and hypotheses, and ethical considerations of the study. The chapter concludes with a discussion of the opportunities for possible social change implications.

Setting

This study partnered with the DMV in the states of Virginia and Maryland. The Virginia DMV and the Maryland MVA wished learn if this program had value. They both provided the data that were cleansed and verified, in order to have valid information. This data were used to determine the age demographic of those registering and if opting out of the heart icon program had any effect on registration. The statistical data analysis was rigorous and extensive in order to authenticate the data.

Research Questions and Hypotheses

RQ$_1$: To what extent does the ability of registered organ donors to opt out of the heart icon program, increase registration rates?

H_{01}: Allowing Maryland registered organ donors to opt out of the heart icon program will increase organ donor registration rates.

$H_1$1: Allowing Maryland registered organ donors to opt out of the heart icon program will not increase organ donor registration rates.

RQ$_2$: What age demographic is holding down registration rates?

H_O2: Specific age ranges can be identified as those opting to not register as donors, and thus hold down the registration rates.

$H_1$2: No specific age ranges could be identified as those opting to not register as a donor, and thus hold down the registration rates.

The first hypothesis allowed for a measurement of the independent variable. The increase in registration rates were measured of those who register as an organ donor, but who opted out of the heart icon program. The independent variable was the policy to opt out of the heart icon program. The dependent variable was registration rates. Over time, the impact of this independent variable could be significant. In addition, the independent variable of age also had an impact on the total donor registration rate. The second hypothesis was used to measure those who opted out of the heart icon program. It was found that an insignificant number of people opted out; thus, it had no impact on the registration rates.

Role of the Researcher

The researcher ensures the standardization and validity of the data. The researcher’s role is to facilitate the process and to conduct the study with the appropriate objectives and protocols. The researcher is also required to discern the relationship between the variables and gain an understanding of the results of the research.

Methodology

The targeted populations for this study were those who had registered as organ donors in the states of Virginia and Maryland for the timeframe specified for this study. From these populations, it was learned about choices that were made when options became available, and the age demographic of those who registered as organ donors. Understanding the age demographic of those who registered as a donor will shed light on the age demographic that does not. This information will prove to be valuable for future efforts to educate this group about donation.

Maryland was chosen for this study, as it was the only state to offer the option of registering and remaining anonymous. Virginia was chosen, as it is geographically close to Maryland and demographically similar. Virginia was also on interested in increasing registration rates and learning if this program had value. Data were provided for this study by the DMV in Virginia and the MVA in Maryland.

Sample

The sample size for this study were all those who registered as organ donors between October 1, 2014 through September 30, 2015, and October 1, 2015 through September 30, 2016. These dates provided comparison from when the option to remain anonymous was not available and when the option became available. DMV and MVA provided the data.

Quantitative methods such as regression displacement, interrupted time series analysis, auto correlation analysis and Arima Box Jenkins time series autoregression were employed. SPSS , Stata and R software were used to examine and analyze the data and to evaluate the results.

Data Collection and Instrumentation

The DMV in Virginia and the MVA in Maryland agreed to provide the data for the timeframes requested. The data requested had specifics that included the total number of those who registered as organ donors, the total number of those who registered to be an organ donor by sex and specific ages ranges, the total number of organ donors who registered by month, and the total number of organ donors who registered but opted out of the heart icon program. Data for donations were calculated as a percent of total motor vehicle transactions. The instrumentation is the data variables.

Data Analysis

SPSS, R and Stata software were used. Regression displacement, interrupted time series analysis, auto correlation analysis and Arima Box Jenkins were employed. The data was coded and summarized during every step throughout the process. Graphs and charts were used to strengthen the understanding of the findings. Previous work studies provided baselines for this topic of research.

Threats to Validity

The data collected came from the main source of organ donor registration in both Maryland and Virginia. There were a few threats to the validity of these data. One possible threat was that computer problems might have generated incorrect data. In addition, data entry errors might also have presented a threat to validity. It is assumed that the MVA and DMV were trustworthy sources of data and that the data were correct and valid.

Issues of Trustworthiness

The data for this study were dependable and credible and were provided by the states of Maryland and Virginia. Both states had verified the validity and overall reliability of these data which ensured the same results of this research. Care was taken in collecting and in analyzing the data, in order to ensure the quality of the data gathered (Creswell, 2013).

Ethical Considerations

Ethics remained the most critical of all considerations in the implementation and design strategy of data collection. The key to ethical consideration was to anticipate any possible dilemmas or questions that may have developed over the course of the research. While reviewing the data, consultation with other professionals was advised. Confidentiality was of the utmost importance. The data received for this study from the

DMV and MVA did not include any confidential material. The accuracy of the obtained information remained a key focus.

Implications for Social Change

Any effort to save a life is considered valuable. The ability to save lives through organ donation is honorable. To have an impact on social change, this study must provide an opportunity to alter human behavior and/or cultural norms and values. In this study, it was learned how to increase the number of those who register as organ donors, which may increase the population for those available to save lives upon their death. By studying the effect of new options for organ donation, it may be possible to increase the likelihood that more people will register to become donors. The goal should be to provide policy to increase organ donor registration. This study provided a blueprint for future possibilities to be considered for others moving forward. If scholars can learn how to impact social behavior regarding organ donor registration, people may increase their organ donor registration rates, and thus save lives. Many lives will be saved, and hopefully fewer people will die waiting for the gift of life.

Summary

The purpose of this study was to learn if providing different options when registering as an organ donor will increase the registration rates of organ donors. The objective was achieved by using a quantitative method to analyze the data provided by the states of Virginia and Maryland’s DMV. Maryland was attempting to increase donor registration rates by allowing those who may believe in myths about donation to remain anonymous as they register. In this study, it was examined to learn if this option proved to increase registration rates. In addition, it was desired to determine if the age of those who register as donors plays a role in registration numbers in these states.

This chapter included a description of the methodology that was used to achieve this goal. A brief overview was presented, as well as the description of the variables that were used. The statistical components were outlined, as well as the research questions and the hypotheses used in the study.

Chapter 4: Results

The purpose of this study was to quantitatively examine whether the efforts by the state of Maryland to provide registered organ donors an option to remain anonymous increased donor registration rates. The research questions and hypotheses that guided the study were as follows:

RQ$_1$: To what extent does the ability of registered organ donors to opt out of the heart icon program, increase registration rates?

H_{01}: Allowing Maryland registered organ donors to opt out of the heart icon program will increase organ donor registration rates.

$H_1$1: Allowing Maryland registered organ donors to opt out of the heart icon program will not increase organ donor registration rates.

RQ$_2$: What age demographic is holding down registration rates?

H_O2: Specific age ranges can be identified as those opting to not registered as donors, and thus hold down the registration rates.

$H_1$2: No specific age ranges could be identified as those opting to not register as donor, and thus hold down the registration rates.

Data Collection

The MVA of Maryland began the program to allow citizens to register as an organ donor and to opt out of the heart icon program as of October 1, 2015. Data from October 1, 2015 through September 20, 2016 were collected. In addition, for comparison, the same data of those who registered as donors from October 1, 2014 through September

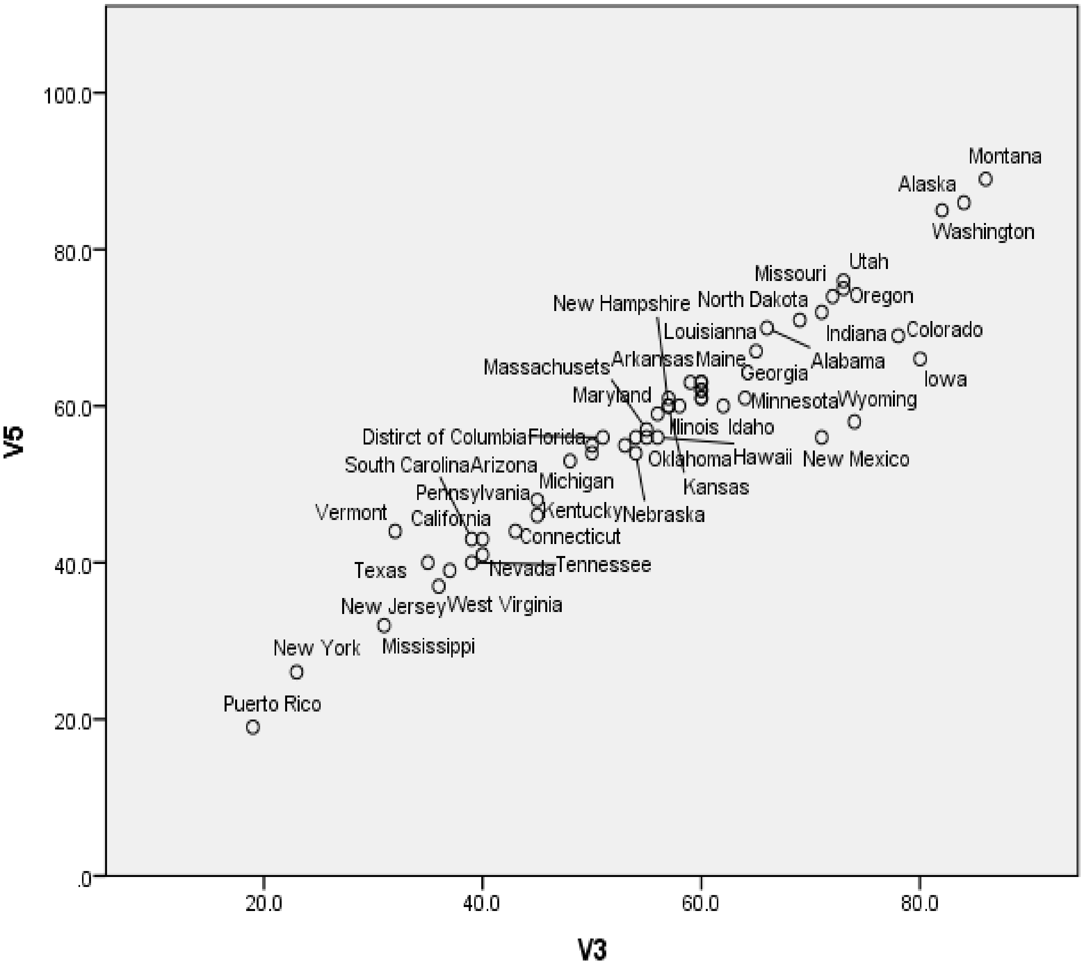
2015 were. The data collection proceeded as outlined in Chapter 3. All participants were 18-years-old or older from the states of Maryland and Virginia.

In the United States, organ donors have to opt in as a donor. Ninety-seven percent of all those who register as organ donors do so at their local DMV (Rodrigue et al., 2012). The states have used multiple methods to try to increase the donor registration rates, ranging from web-based registration to marketing methods using social media. The results have been mixed. Social media can bolster organ registration rates (Feely & Kruegler, 2015).

Study Results

Research Question 1

A regression displacement analysis using registered donations for 2014 and 2015 data from the 52 jurisdictions for all 50 states and the District of Columbia and Puerto Rico was conducted to understand whether the states of interest, particularly Maryland, exhibited any patterns worth noting. The regression equation $Y_{2015} = \beta_0 + BX_{2014} + \varepsilon$ was fitted to the data. The resulting equation $Y_{2015} = 7.934 + .879^{**}X_{2014}$, R^2= .90 shows a strong linear pattern as shown in Figure 1.



Note. V3 = 2014 Rates   V5 = 2015 Rates

Figure 1. Organ donor registrations in the American states 2014-2015.

Maryland was in the middle of the pack, almost on the regression line. A scatter diagram of the forecasted values plotted against the actual value in Figure 2 shows the same pattern, much the typical state in terms of donor registration rates.

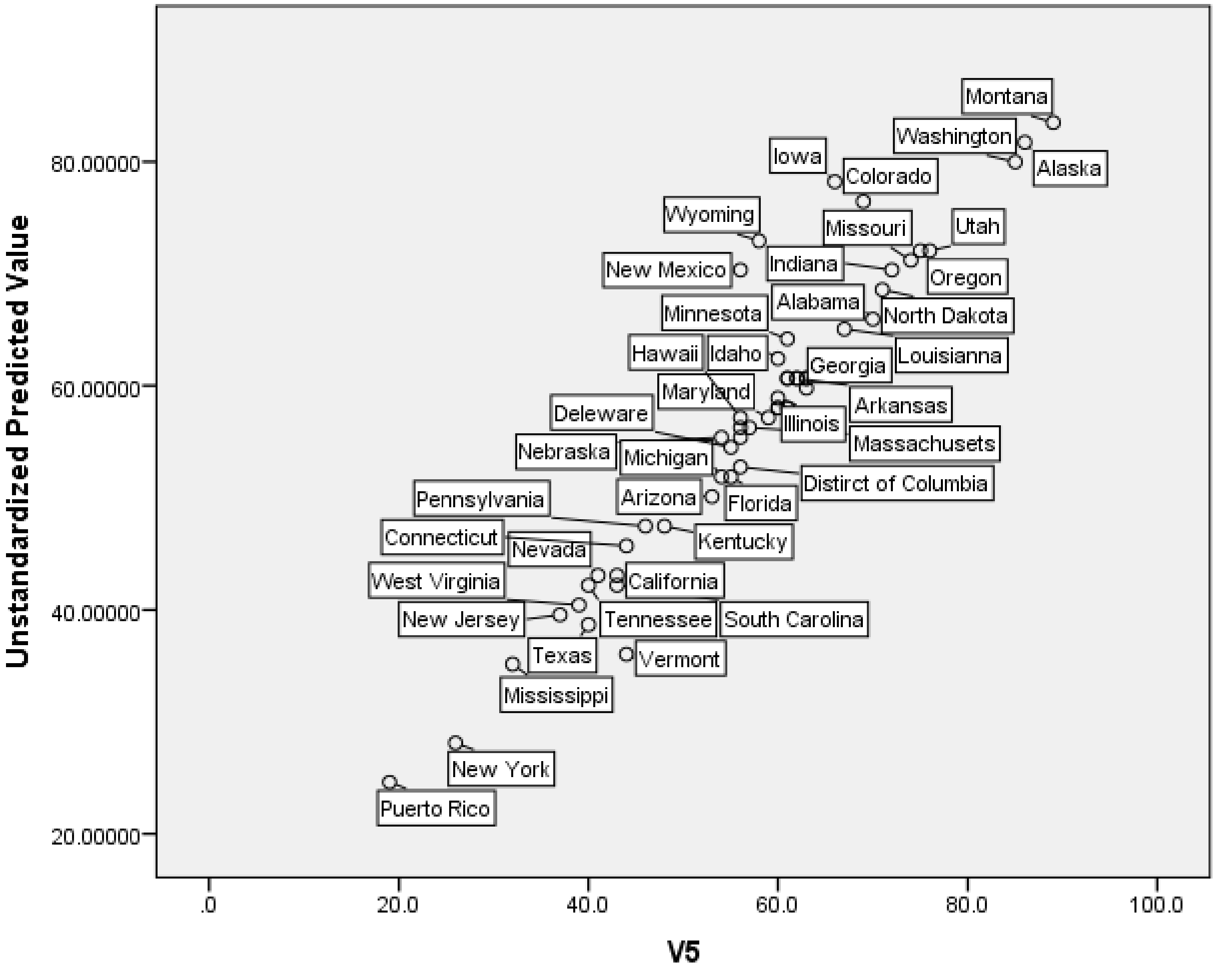


Figure 2. Donor registration rates by states.

Maryland was chosen for this study, as it was the only state to offer the option of registering and remaining anonymous. The heart icon on the driver’s license is a nationally recognized symbol of registered organ donors. The state of Maryland’s option to allow registered organ donors to opt out of the heart icon program might serve as a test of whether anonymity increases the rate of organ donation. The term opt out here is not used in the same manner as the better known opt out options in European countries, but rather to denote that prospective donors in Maryland can decide to remove the heart icon from their driver’s licenses. No other state in this country has offered the option of allowing registered donors to register but opt out of the heart icon program, allowing them to remain anonymous. In order to understand the impact of this program, comparing the results to a state without this program could provide data to understand if providing this option had value. The state of Virginia was chosen as they had similar demographics and populations. A comparison of time series data on organ donations for Maryland and Virginia over a 2-year period including the policy intervention was conducted. Virginia originally was the control group and the periods before and after the intervention in both Maryland and Virginia were compared.

The data for the study encompassed 30 consecutive months for both Maryland and Virginia from April 2014 through September of 2016. The intervention occurred in October 2015. Attempts to collect additional data both for earlier and later months of the intervention both for Maryland and Virginia were unsuccessful. The relevant time series graphs for the registration rates as a percent of total DMV transactions are depicted in Figures 3,4, and 5.

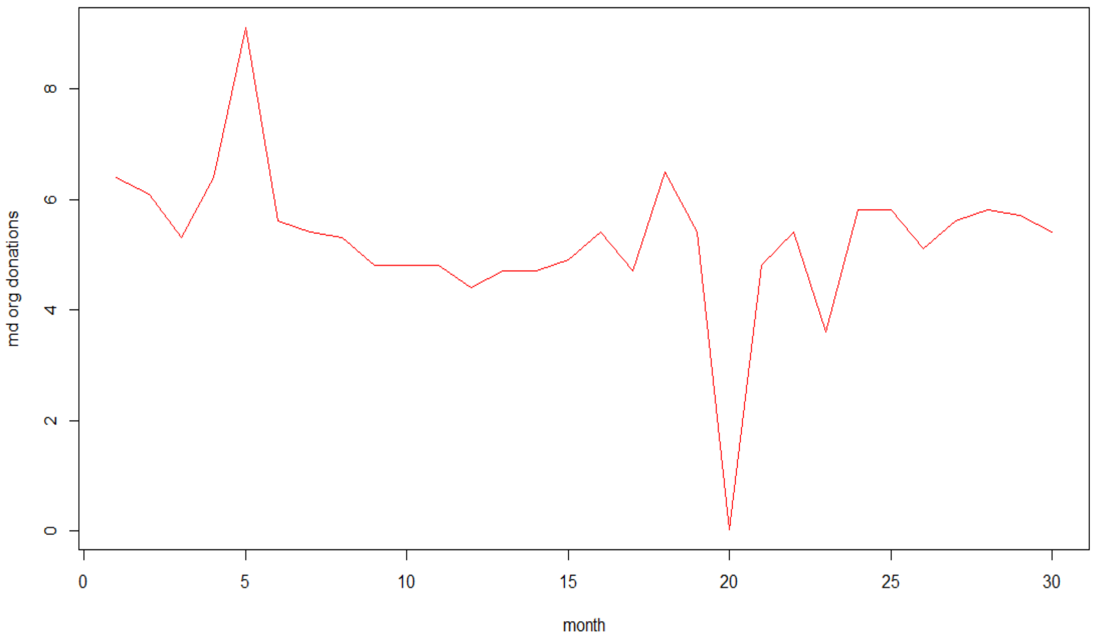
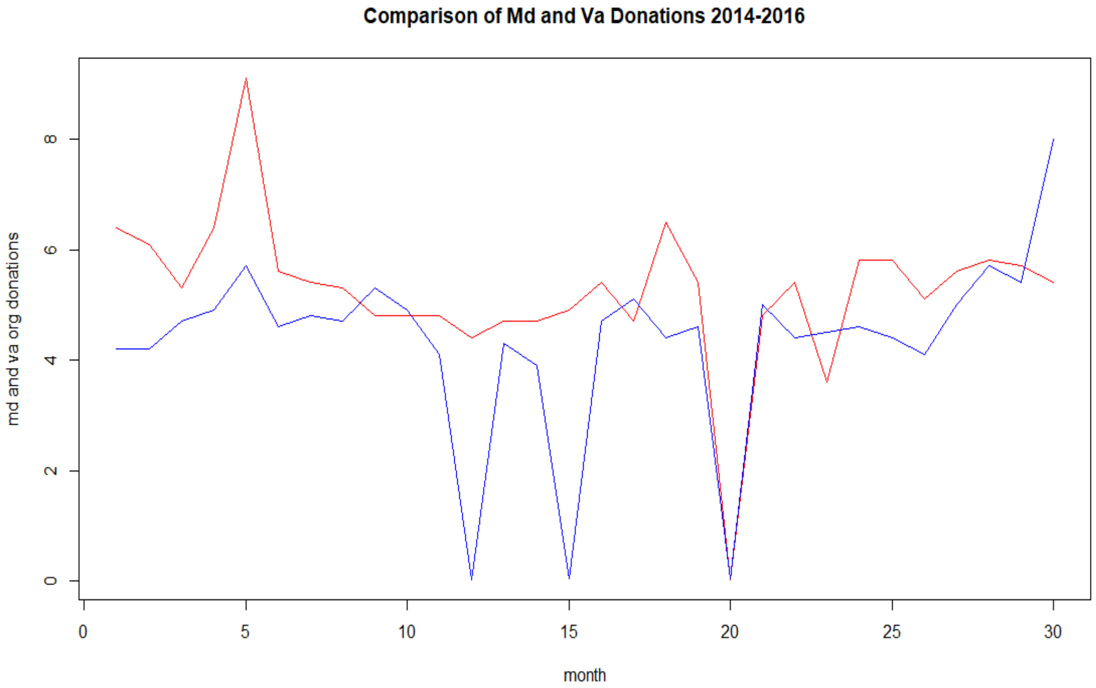
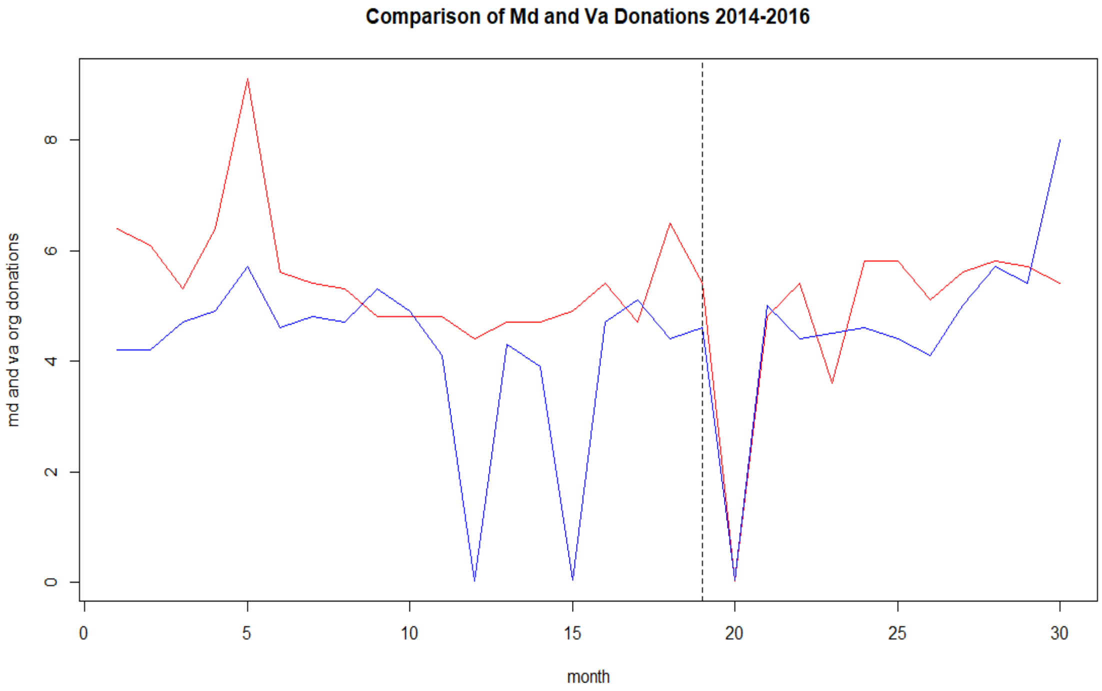


Figure 3. Maryland organ donor registration rates as percent of total DMV transactions 2014 -2016.



Note. Maryland Red, Virginia Blue

Figure 4. Virginia donor registration rates and Maryland rates.



Note. Maryland Red, Virginia Blue

Figure 5. Donor registration rates with policy intervention.

The different plots, on visual examination, show no discernible trends. In addition to the registration rates, the program intervention HTOPT was coded as a dummy variable, coded 0 before the intervention and 1 on and after October 2015. This variable captures the interplay between the intervention and time. A time variable, time was added to capture the overall secular trend over the 30-time periods. A variable TimeAft was coded 0 before the intervention and numbered sequentially after the intervention to capture the continuing effect of the HTopt program. Lastly, a difference DID variable was added to measure the differences between Maryland and Virginia rates. Virginia's rates exceeded Maryland's rates in 7 months out of the 30-month series. Runs tests were calculated for the Maryland, Virginia, and DID variables. The runs test for randomness is a simple numeric check for the randomness of a time series. The following table shows the results

Table 1

Runs Tests

Variables	Maryland rates	Virginia rates	Difference variable
Mean	-1.512	-2.272*	-.349
Median	-.908	-1.224	-.535
Mode	-.908	-2.028	-.770

Note. *=*P*<.05

The absence of significant p-values for the Maryland and difference variable indicated that there was no evidence to reject the hypothesis of a random process. Despite this visual inspection of the Maryland data, further examination is suggested. Regression equations using time as the independent variable prior to the month of the intervention and after the month of the intervention tests to show whether there were two different dynamic processes at work was used. Prior to October 2015, the fitted regression; $Dpct\ md = 6.369 - .090Time$ suggested a negative, if insignificant, trend. After October 2015, the series for both states spiked downward, which could be attributable to chance but the fitted regression after the intervention; $Dpct\ md = -3.122 +$

$.318Time *$ showed a positive, but significant slope, which may have been caused by the outlier at the end of the series. Regressions were also fitted for the DiDpct variable. Prior to October 2015, the regression equation for the variable was $DiDpct = 1.433 - .006Time$. After that month, the fitted equation was $Didpct = 2.638 - .099Time.$ None of the slopes showed significance.

To analyze further the interrupted time series regression equation, $Y = \beta_0$+β_1T+β_2Hopt+β_3,Time Aft was fitted to the both the Maryland rates and the difference in Maryland and Virginia rates. Table 2 shows the results of the interrupted time series.

Table 2

Interrupted Time Series Analysis: Impact of the Removal of the Heart Option

	Coefficient	Standard Error
Maryland		
Time	-.090	.056
Hopt Intervention	-1.329	.945
Time Aft	.312**	.118
Intercept	6.369**	.608
RSquare .260		
Durbin Watson 2.202		
Difference Md Va		
Time	-.006	.694
Hopt Intervention	-.447	1.078
Time Aft	-.094	.134
Intercept	1.433*	
R square .175		
Durbin Watson 2.009		

Note. *p*<.01 * p<.05

It was found that the level of organ donation rates in Maryland showed a decrease of 1.3% after the intervention according to β_2. In addition, β_1 and β_3 showed that rates decreased before the intervention point (-.090), but it showed an increase (.312-.090=.222) afterwards. Given the lingering effects of autocorrelation and the Durbin Watson statistics for both models, regression in this interrupted time series is normally estimated in autoregressive form, where:

$Y_t = \emptyset_t Y_{t-1} + \emptyset_2 Y_{t-2} + \ldots \emptyset_p Y_{t-p} + \alpha_t$

The best predictor of the variable at time t was the variable at t-1 and α_t is the error term. In accordance with the method, correlograms and partial correlograms were generated for both the Maryland rates and the difference between the two state rates. Figures 6, 7, 8, and 9 show the correlograms and partial correlograms.

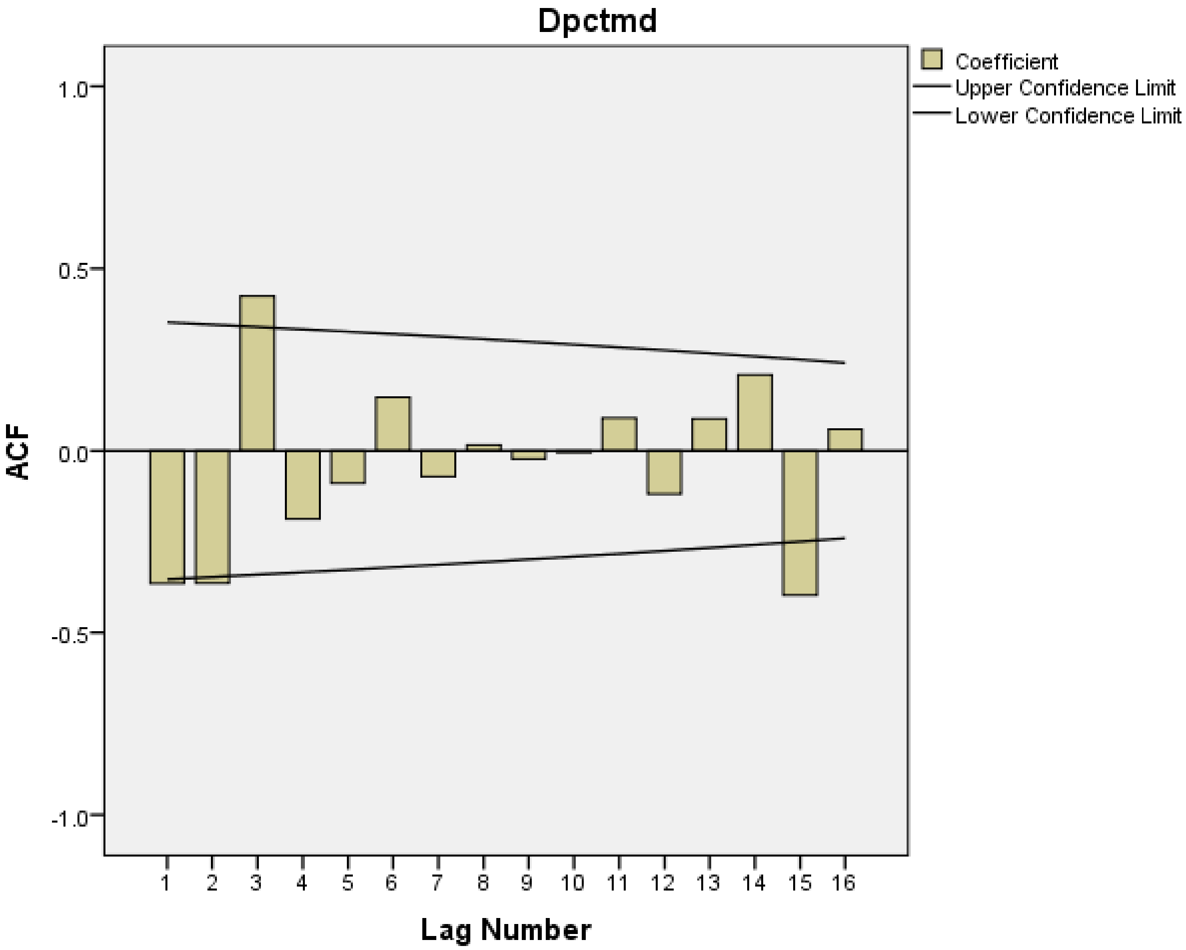


Figure 6. Maryland Rates.

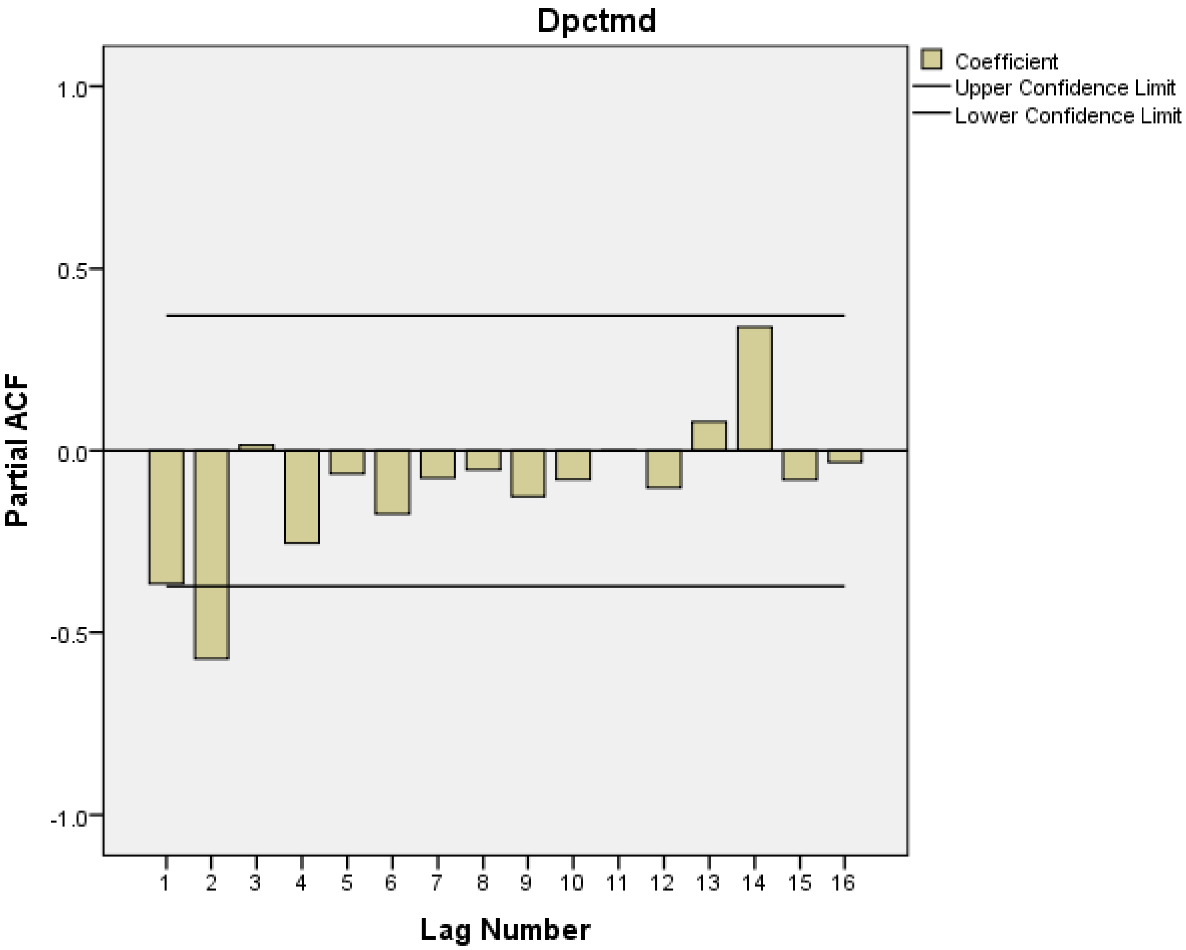


Figure 7. Partial Correlogram: Maryland.

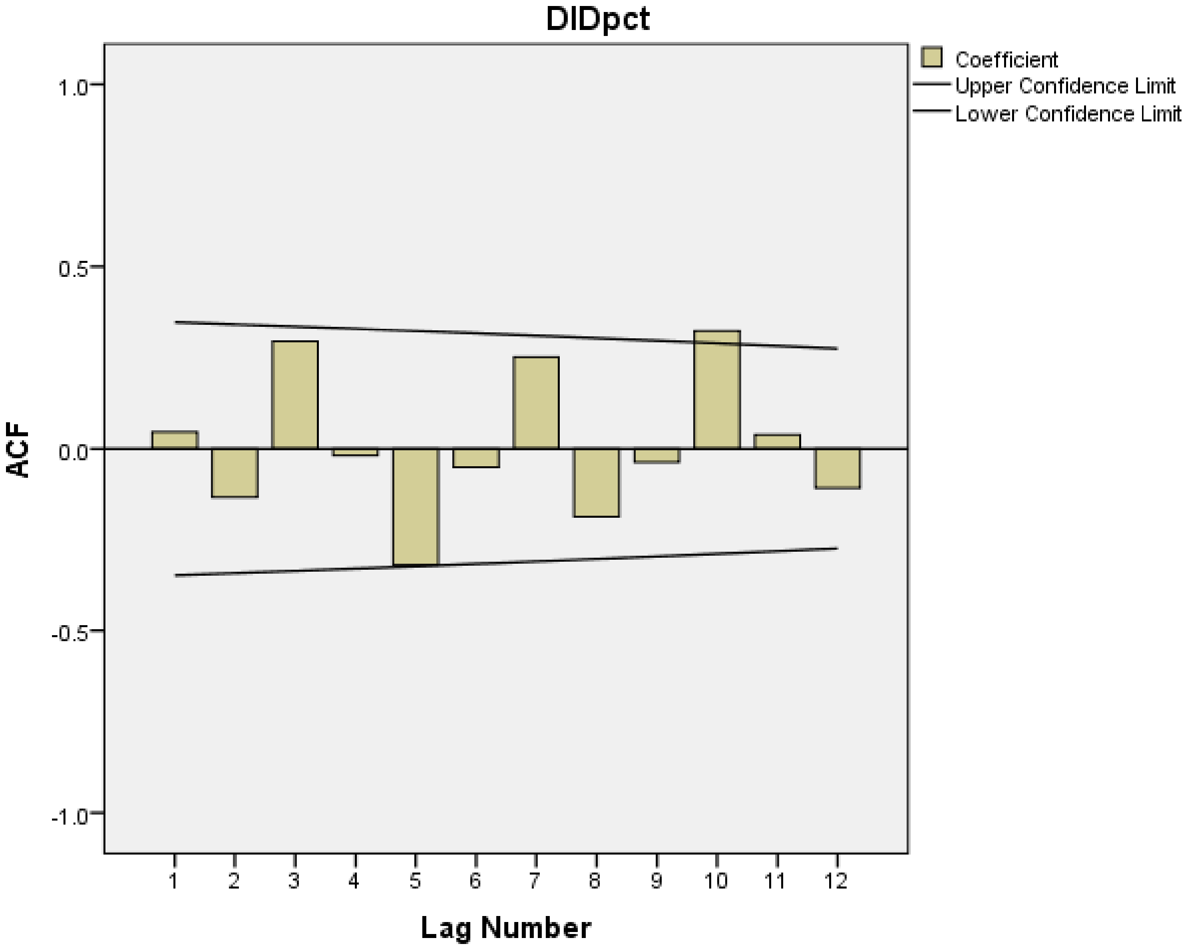


Figure 8. Correlogram: Difference between Maryland and Virginia

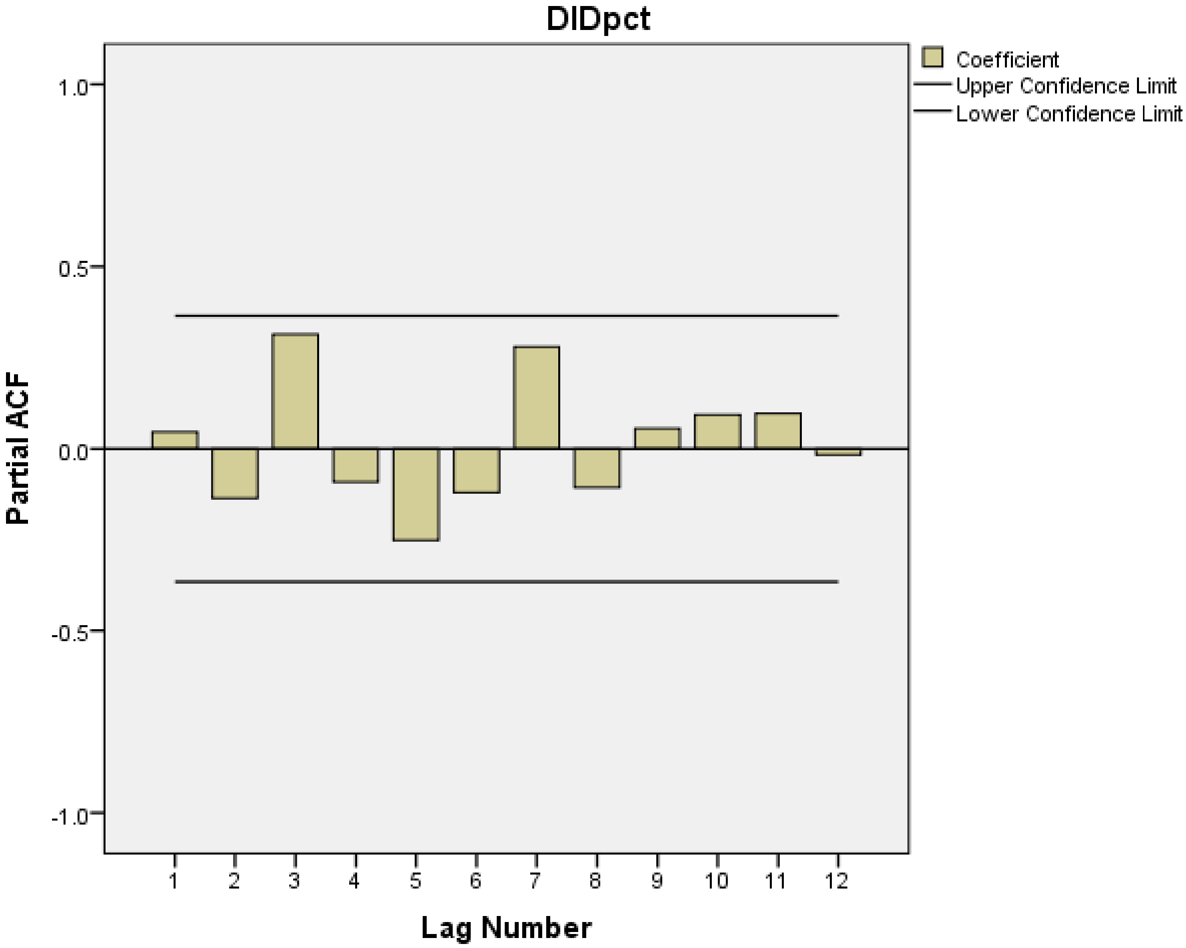


Figure 9. Partial Correlogram: Difference between Maryland and Virginia

The ACF and PACF charts for both variables did not match patterns that are classified into autoregressive or moving average patterns. The estimation of the parameters using ARIMA modelling might be of some help. Parameters were estimated for ARIMA (0,0) and a first order ARIMA (1,0) process. Table 3 displays the results for the Maryland rate data only. Results for the difference between Maryland and Virginia were not shown, as none of the parameters showed significance both using the random noise model or the first order autoregression.

Table 3

Parameter Estimates for Maryland Registration Rates

Variable	Parameter estimate	Standard error	*P*-value
AR(1)			
Time	-.006	.053	.101
TimeAft	.316	.110	.008*
HTopt	-1.349	.902	.147
AR(0,0)			
Time	-.090	.056	.123
TimeAft	.312	.118	.014*
HTopt	-1.329	.945	.172

The parameter estimates for the variables showed the sole significance of the TimeAft variable both in the first order AR process and in the random noise model. There may be some significance to the erratic upward trend that started about the 20th month after the intervention. The coefficient measured the continuing effect of the policy after enactment and should capture long-term impact. The coefficient for time here was treated as a nuisance variable, as it controlled for any secular trend effect. The coefficient for the intervention variable again appeared insignificant. There does appear to be some evidence, although weak, that there may be a long-term impact of the removal of the heart icon option. The theory of planned behavior helps to explain the attitudes toward organ donation.

Research Question 2

Looking at the data from October 1, 2015–October 1, 2016, it was found that the largest population to register as donors was the 18- to 30-year-old age group. As the population ages, organ registration decreased. The age group of 51-60 years of age was the population registering the least. However, all ages from 31-years-old and above registered as a much lower rate than those in the 18– 30-year-old range. This answered the question, what age demographic is holding down registration rates. $H_0 2$ was correct in that there is a specific age range that can be identifies as holding down registration rates. This information could be useful in educational efforts to increase registration rates. Figure 10 shows the registered donors by age.

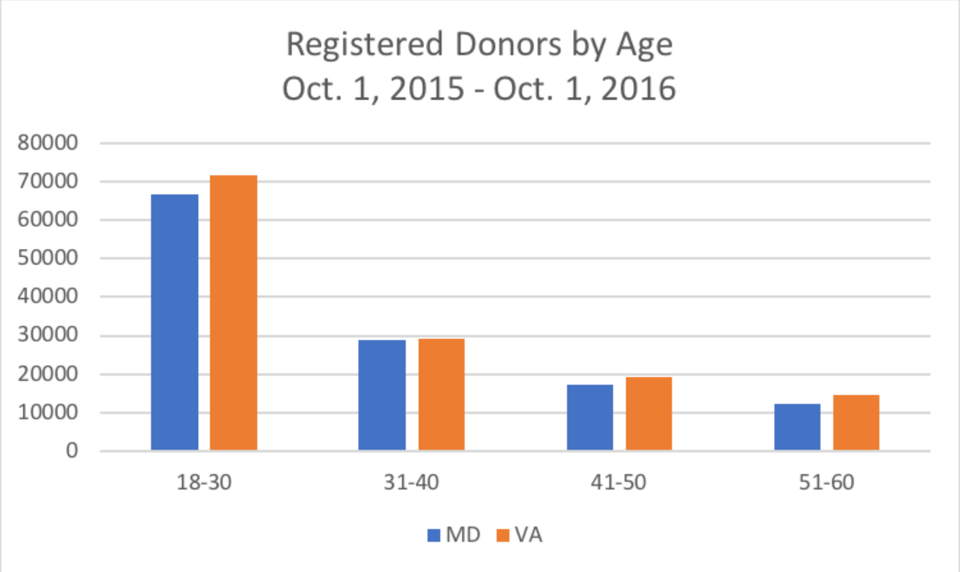


Figure 10. Results of registered donors by age.

Summary

The data were not made available past September of 2016 to further investigate the viability of a long-term impact. A more extensive time series could better explain what appears to be a volatile period within which the policy change took place. There is the possibility of a history threat or possible cointerventions, such as changes in variables that could affect changes in donation registrations. For example, Maryland state employees were convinced that increases in donor rates were due to the governor's push to emphasize on line transactions for registrations (The Baltimore Sun, 2018). This policy push was initiated in 2014 prior to the beginning of the series, but data for that period was unavailable. There were also other variables that affected donor registration; but, they were beyond the scope of the data in this study. The rates may vary on the basis of age, education, and other relevant demographics.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this quantitative study was to examine the impact of offering registered organ donors the option of remaining anonymous. Two research questions guided this study. In the first question, it was tested the extent of opting out of the heart icon program and the impact it had on registration rates. In the second question, it was tested if any age demographic held down registration rates.

Previous researchers did identify that the myth of trusting the medical profession and their access to see the heart on their driver's license was a problem. The belief that a doctor will be more interested in recovering organs than saving a life was a prominent reason for not registering as an organ donor (Hyde et al., 2012). Ethnic minorities cite the mistrust of the medical community as the second most common reason to not register as an organ donor (Brown, 2012). Tribal College communities also expressed the same mistrust (Jernigan et al., 2013). The mistrust of the medical community in relation to organ donation was apparent in all focus group, regardless of race (Quick et al., 2012). Morgan et al. (2013) showed the mistrust of the medical profession with African Americans and the Black Caribbean population. Regarding the age of those who register to donate, mature adults are more likely than those younger to not register as a donor (Quick et al., 2016). However, no previous research was done on the option of opting out of the heart icon program, allowing the registered donors to remain anonymous. This study was conducted to understand the impact of the ability of registered donors remaining anonymous.

Nature of the Study and Key Findings

Data were collected from the MVA in the state of Maryland and the DMVs in the state of Virginia. All donor registration data were collected for the time range of April 2014 to October 2016. According to the overall results, it was not found that offering the option to remain anonymous and registering to be an organ donor with no heart icon on the driver’s license encouraged more people to register as an organ donor. It was also learned that there were certain ages were less like to register as an organ donor. The age bracket 31-years-old and older registered at a much lower rate than those in the 18–30-year-old range.

This chapter provides an interpretation and analysis of these results, including the limitations of the study, as well as recommendations for further research and implications for social change.

Interpretation of the Findings

Maryland offered the opportunity to not receive the heart icon on a driver’s license when registering as an organ donor; however, it did not find that this impacted registration rates in a positive way. As discussed in Chapter 2, there is a mistrust of the medical community when it comes to organ donation (Quick et al., 2012). Although some did opt out of the heart icon program, it is difficult to conclude that offering the opportunity to remain anonymous would encourage organ donor registration. Although the analysis was suggestive, there were not enough data to make this case. In addition, the age group of 18-30-year-olds was the population most likely to register as organ donors. Previous research supports efforts to register a wider range of donors (Quick et al., 2016).

Limitations of the Study

The limitation of the study was that a larger range of data were not made available for further investigation. The data for the study encompassed 30 consecutive months for both Maryland and Virginia from April 2014 through September of 2016. The intervention occurred in October 2015. Attempts to collect additional data both for earlier and later months of the intervention both for Maryland and Virginia were unsuccessful. A more extensive time series could better explain what appears to be a volatile period within which the policy change took place. There is the possibility of a history threat or possible cointerventions, such as changes in variables that could affect changes in donation registrations. For example, some Maryland state employees believe that increases in donor rates are due to the governor's push to emphasize online transactions for registrations (The Baltimore Sun, 2018). This policy push was initiated in 2014 prior to the beginning of the series and was unable to obtain data for that period. There were also other variables that affect donor registration; but they, were beyond the scope of the data in this study. The rates may vary on the basis of age, education, and other relevant demographics. Certain demographics are less likely to register and that could also have been a limitation to this study (Brown, 2012). As defined in Chapter 2, additional research is needed to understand why people choose to not register as organ donors (DuBay et al., 2014).

Implications for Positive Social Change and Recommendations for Practice

Any effort to save a life is considered valuable. The ability to save lives through organ donation is honorable. To In this study, provided an opportunity to alter human behavior and/or cultural norms and values. By studying the effect of providing new options for organ donation, it may be possible to increase the likelihood that more people will register to become donors. The goal should be to provide policy and opportunities to increase organ donor registration. If scholars can learn how to impact social behavior regarding organ donor registration, increase the organ donor registration rates, and save lives, the implications for social change are immeasurable. Many lives will be saved, and fewer people will die waiting for the gift of life.

Conclusions

Although there was no strong evidence that offering registered organ donors the option of remaining anonymous increases registration rates, the policy may have an increasing impact over the long term. This long-term impact can only be confirmed with additional data. There is considerable value in learning the effectiveness of different strategies to encourage organ donor registration. Regarding the age of those who register to be organ donors, further research should be done to understand why those 31-years-old and older are registering to become an organ donor at a much lower rate than those younger. Understanding how to encourage this age category to agree to organ donation could impact registration rates. Organ donation saves lives, and research to understand how to register more donors has value.

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