**Name of Journal:** *World Journal of Transplantation*

**Manuscript NO:** 84040

**Manuscript Type:** ORIGINAL ARTICLE

***Observational Study***

**Randomized intervention to assess the effectiveness of an educational video on organ donation intent among Hispanics in the New York metropolitan area**

Pekmezaris R *et al*. Intervention to increase organ donation intent

Renee Pekmezaris, Edgardo Cigaran, Vidhi Patel, Damian Clement, Christine L Sardo Molmenti, Ernesto Molmenti

**Renee Pekmezaris, Edgardo Cigaran, Vidhi Patel, Damian Clement, Christine L Sardo Molmenti,** Feinstein Institutes for Medical Research, Northwell Health, Manhasset, NY 11030, United States

**Ernesto Molmenti,** Department of Nephrology, Northwell Health/Zucker School of Medicine at Hosftra, Manhasset, NY 11030, United States

**Author contributions:** Pekmezaris R, Patel V, and Molmenti E designed and supervised the study; Cigaran E conducted data analysis and interpretation, and drafted the manuscript; Pekmezaris R, Patel V, Molmenti E, and Cigaran E conducted a literature review; Clement D contributed to data analysis and interpretation; Sardo Molmenti CL revised the manuscript critically for intellectual content; Molmenti E and Pekmezaris R approved the final version of the paper.

**Corresponding author: Edgardo Cigaran, MS, Research Fellow,** Feinstein Institutes for Medical Research, Northwell Health, 600 Community Dr, Manhasset, NY 11030, United States. edgardo.cigaran@gmail.com

**Received:** March 2, 2023

**Revised:** May 4, 2023

**Accepted:** May 23, 2023

**Published online:**

**Abstract**

BACKGROUND

The Hispanic community has a high demand for organ donation but a shortage of donors. Studies investigating factors that could promote or hinder organ donation have examined emotional video interventions. Factors acting as barriers to organ donation registration have been classified as: (1) Bodily integrity; (2) medical mistrust; (3) “ick”-feelings of disgust towards organ donation; and (4) “jinx”-fear that registration may result in one dying due to premeditated plans. We predict that by providing necessary information and education about the donation process *via* a short video, individuals will be more willing to register as organ donors.

AIM

To determine perceptions and attitudes regarding barriers and facilitators to organ donation intention among Hispanic residents in the New York metropolitan area.

METHODS

This study was approved by the Institutional Review Board at Northwell Health. The approval reference number is No. 19-0009 (as presented in Supplementary material 1). Eligible participants included Hispanic New York City (NYC) residents, 18 years of age and above, who were recruited voluntarily through Cloud Research and participated in a larger randomized survey study of NYC residents. The survey an 85-item Redcap survey measured participant demographics, attitudes, and knowledge of organ donation as well as the intention to register as an organ donor. Attention checks were implemented throughout the survey, and responses were excluded for those who did fail. Participants were randomly assigned two-between subject conditions: To view a short video on organ donation and then proceed to complete the survey (*i.e.*, video first) and view the same video at the end of the survey (video last). No intra-group activities were conducted. This study utilized an evidenced-based emotive educational intervention (video) which was previously utilized and was shown to increase organ donation registration rates at the Ohio Department of Motor Vehicles. Results were analyzed using Jamovi statistical software. Three hundred sixty-five Hispanic individuals were included in the analysis. Once consent was obtained and participants entered the survey (the survey sample is presented in Supplementary material 2), participants were asked to report on demographic variables and their general impression of organ donation after death. The video depicted stories regarding organ donation after death from various viewpoints, including from the loved ones of a deceased person who died waiting for a transplant; from the loved ones of a deceased person whose organs were donated upon death; and, from those who were currently waiting for a transplant.

RESULTS

Using a binomial logistic regression, the analysis provides information about the relationship between the effects of an emotive video and the intention to donate among Hispanic participants who were not already registered as donors. The willingness to go back and register was found to be significantly more probable for those who watched the emotive video before being asked about their organ donation opinions [odds ratio: 2.05, 95% confidence interval (1.06, 3.97)]. Motivations for participation in organ donation were also captured with many stating the importance of messages coming from “people like me” and a message that highlights “the welfare of those in need”. Overall, the findings suggest that using an emotive video that addresses organ donation barriers to prompt organ donation intentions can be effective among the Hispanic populous. Future studies should explore using targeted messaging that resonates with specific cultural groups, highlighting the welfare of others.

CONCLUSION

This study suggests that an emotive educational intervention is likely to be effective in improving organ donation registration intent among the Hispanic population residing in NYC.

**Key Words:** Community engagement and health; Health equity; Diversity and inclusion; Health policy; Kidney donation; Minority health and disparities; Organ transplant

Pekmezaris R, Cigaran E, Patel V, Clement D, Sardo Molmenti CL, Molmenti E. Randomized intervention to assess the effectiveness of an educational video on organ donation intent among Hispanics in the New York metropolitan area. *World J Transplant* 2023; In press

**Core Tip:** The Hispanic community has a high demand for organ donation but a shortage of donors. A study conducted in New York City found that providing an emotive educational video on organ donation before taking a survey significantly increased the odds of organ donation intent among Hispanic individuals. By providing necessary information and education about the donation process, Hispanic residents can be just as willing to become organ donors as their non-Hispanic counterparts.

**INTRODUCTION**

As of March 2022, more than 105800 men, women, and children were on the United States national transplant waiting list, while just over 40000 organ transplants were performed in 2021, creating a deficit in which 17 people die each day while waiting for an organ transplant[1]. This issue can be viewed from many different perspectives, such as allocation systems, registration processes, cultural barriers, and even geographic considerations. Our goal is to highlight barriers and possible solutions to the dearth of organ donation registration in the State of New York, which has the lowest organ donation rate in the country[2]. Specifically, the primary objective of this study is to test the effectiveness of a best practice educational video intervention to improve registration amongst Hispanic residents of the New York metropolitan area. Specifically, we will examine a representative sample of Hispanic respondents randomized to this best practice intervention, a subset of a previously published large study of New York residents, to focus on the Hispanic population to elucidate possible solutions to this significant and unfortunate shortage of lifesaving organs.

The organ donation process has a long legislative history that is not common knowledge nor without controversy[3]. In 1968, the United States passed the Uniform Anatomical Gift Act, creating a national organ transplantation policy[4]. Currently, the United Network for Organ Sharing maintains the organ procurement and transplantation network, a system established by the National Organ Transplant Act of 1984[4]. The goal of nationalizing the organ donation process and creating supporting networks was to create an effective and efficient organ-sharing system organized into 11 geographic regions[4]. Following the nationalization in 1998, the Former DHHS Secretary Donna Shalala issued the Final Rule policy to process organs more equitably[4]. The purpose of the policy is to match donors and recipients based on statistical consideration of both clinical parameters and proximity to the location of the organ donor. Before these rulings, states with larger donation banks benefited from distribution systems that favored locality, but allocation systems have now incorporated national needs. New York has explicitly unique difficulties that benefit from such policies, as they make up for 10% of the national organ transplant waiting list, yet they have the lowest donation rates[2]. NYS organ donation rate is a meager 35%, compared to the national average of 58%, and the highest-ranking state of Colorado, with a donation rate of 69%[5,6]. As a result, nearly 10000 New Yorkers are currently waiting for an organ[7].

Legislative initiatives intended to improve transplant systems have been effective, but literature reviews on improving donation rates at the individual level have taken on a human factor approach[3,8]. This angle is of critical importance given the donation rates among racial/ethnic minority populations. The national transplant waiting list stands at 105464 people; 60.0% of those waiting represent racial and ethnic minorities[9]. Hispanics alone comprise 20.5% of the transplant waiting list[10]. Targeting organ donation initiatives to populations that are most at risk is vitally important in NYS, as increased diversity in donor populations can lead to increased access to transplantation and a better chance of finding close matches in terms of shared genetic background[4]. Hence, increasing registration rates among immigrant populations, of which NYS currently holds the second-largest ranking in the country, is key[11]. Donation trends by underrepresented minorities have always been historically low when compared to white individuals[12]. There is some encouraging news regarding donation rates. Specifically, the standardized donation ratio for Hispanic/Latino groups increased from 1.92% in 1999 to 3.35% in 2017[12]. While this increase is noteworthy, it was not significantly different than the increase seen in non-Hispanic/Latino individuals. Despite the benefits of a more diverse donor pool, there is still much to be done to motivate efforts to increase donation rates among Hispanic communities.

Given the great need to improve organ donation in NYS, we seek to identify effective interventions in Hispanic communities. Research looking at hindering factors to donor rates among Hispanic communities identifies factors such as mistrust of healthcare systems, literacy rates, and cultural barriers. For example, Hispanic donors are more likely to develop Clavien grade IV or higher surgical complications (not limited to nervous system complications), conversion to open nephrectomy, intensive care unit stays, and death[13]. Coupled with already existing health disparities such as kidney disease, higher prevalence of incidence of type 2 diabetes, and development of end-stage kidney disease, may add to the negative experiences and mistrust of the healthcare system[14-21]. Other factors that have been reported include insufficient levels of health literacy which has been found to impact organ donation registration and consent from family members[22-26]. Therefore, targeted educational messaging about organ donation is crucial to increase awareness and understanding among individuals. This is especially true when considering individuals’ willingness to disseminate sociocultural tailored content that is shared by existing social ties[27]. Hence, targeted messaging that resonates with specific cultural groups and is shared through existing social connections may be more effective in increasing donation rates.

Educational interventions may include different settings such as schools, departments of motor vehicle (DMV), primary care, and other local community locations[8]. Approaches have included educational sessions and videos, leveraging peer leaders in the community, DMV staff training, messaging, and priming[8]. Other interventions include testing “opt-out” policies, which is a presumed consent model as opposed to the standard “opt-in” policy that exists in the United States[28-32]. Although the “opt-out” model has reported positive results such a policy is not expected to become imminently approved in the United States, suggesting further research into motivations behind organ donation. Our larger study 33 was built around an existing video message directly addressing some of the documented barriers to organ donation. The video was found to be successful in improving registration rates by addressing barriers such as: (1) Bodily integrity; (2) medical skepticism; (3) “ick”-described as a discomfort towards the process; and (4) “jinx”-superstitious around the process of preparing for one’s death[33].

The emotional video messaging used in the Thornton study[34] (as presented in Supplementary material 3) was effective in increasing organ donation registrations at the Ohio Bureau of Motor Vehicles (BMV). Our previous study[32] was also successful in increasing organ donation intent in NYS. While Thornton’s study was conducted at 12 branches of the Ohio BMV, our larger study used a Sample of Amazon MTurk participants located in NYS with randomized exposure to the emotional video. We observed a significant increase in the proportion of respondents who were motivated to register as organ donors among those who were exposed to the emotional movie (randomized to the movie First condition) compared to those randomized to the Video Last condition. Of note, the original video did not use content specific to any particular culture. This paper aims to build on the larger study 32 by focusing on the effects of the video on the Hispanic demographic who viewed the video before (“first” group) administration of a survey of attitudes toward and knowledge of organ donation *vs* those who did not view the video until after survey participation (“last” group).

**MATERIALS AND METHODS**

The study adheres to the principles outlined in the Declaration of Helsinki and all participants provided informed consent before they participated in the study. As described in Table 1, participants (*n* = 365) were enrolled in part of a larger randomized survey study conducted with New York City residents who were recruited *via* a crowdsourcing online platform and were randomized to one of two groups, with exposure to viewing: (1) An educational video before completing an 81-question survey on organ donation (“video first” condition); or (2) after completing the survey (“video last” condition). The survey instrument was investigator-developed in the absence of existing validated tools. Interviews with subject matter experts and a review of the literature were utilized to ensure the topic of the survey is relevant to the population of interest during item creation. Logistic regression analysis compared organ donation intent (*i.e.*, “How likely are you to become an organ donor”) between the two groups. Additional variables related to organ donation (*e.g.*, religious beliefs, financial incentives) were also evaluated between the two groups. Analyses were adjusted for organ donation registration status. Data were analyzed using Jamovi (version 2.3.19), a software package that runs in tandem with R Statistical Software. Frequencies and percentages were used for categorical data. Summary statistics were utilized to describe sample characteristics. To determine parameters that might predict the likelihood of organ donation registration and to assess the effects of the video intervention, we used binomial logistic regression analysis. The clinical and research activities being reported are consistent with the Principles of the Declaration of Istanbul as outlined in the Declaration of Istanbul on Organ Trafficking and Transplant Tourism.

***Participants***

Table 2 presents Hispanic participant characteristics for the total sample by registration status (registered organ donor, non-registered organ donor, and those who did not specify). More than a quarter (35%) of participants identified as White or Caucasian, less than a quarter (15%) as Black or African American, and 18% as multiracial. The majority of participants were female. Seventy-two percent of the sample participants said they were between the ages of 19 and 39; 60% of them reported being single or never married; and 67% said they were employed either full- or part-time. Thirty-eight percent of the sample as a whole had organ donation records after passing away 40% and 38%, respectively, of those who described themselves as spiritual or religious had registered as organ donors. Additionally, 28% of participants with degrees of 2 years or less were registered as organ donors, compared to 45% of participants with graduate degrees or 4-year degrees.

**RESULTS**

***Impact of emotional video***

In the current study of Hispanic participants who were randomly assigned to the Video First condition who had not yet registered as organ donors, were found to be significantly more inclined to do so than those in the Video Last condition [odds ratio (OR): 2.05, 95% confidence interval (95%CI): 1.06, 3.97], according to the results (Table 3). In comparison to those in the Video Last condition, participants in the Video First condition were less likely to be swayed by the donor’s health [OR: 0.53, 95%CI (0.31, 0.90)], more likely to be aware that they could sign up at the DMV [OR: 2.21, 95%CI (1.22, 4.03)], and less in favor of an opt-out system [OR: 0.49, 95%CI (0.25, 0.96)]. Contrasted with the bigger sample, it was discovered that Hispanics in the Video First condition was just as likely as those in the overall sample to express a willingness to register as donors among non-registered donors [OR: 1.64, 95%CI (1.22, 2.20)].

***Driving factors for organ donation***

Table 4 lists reasons for participating in organ donation among the entire sample of participants. According to the findings, 35% of participants thought the message needed to come from a person similar to them, while 11% disagreed and 54% said it made no difference. A majority of participants (58%) said they would be inspired by a message that focused on the welfare of less fortunate people. However, the majority of participants did not have a preference for the demographics of the speaker promoting organ donation, such as their ethnic background or notoriety (44% and 38%, respectively).

**DISCUSSION**

Previous studies have considered the many hindrances that impede registering to be an organ donor, specifically in minority communities. One of the main reasons identified is a lack of awareness and understanding about organ donation among minority communities. Many people in these communities may not be aware of the need for organ donation or may have misconceptions about the process. Additionally, there may be cultural and religious barriers to organ donation in some minority communities. Hence the importance of analyzing this subset of Hispanic participants to highlight some possible avenues of approach to overcome these hindrances using an effective educational intervention.

This analysis found that a previously established intervention had a significant effect on respondent willingness to register as donors. Participants who were not registered and exposed to the Video First condition were more likely to report their intention to register compared to those who were exposed to the Video Last condition. Additionally, our analysis indicates that participants not registered as donors knew they could register at the DMV and favored an opt-out system. When comparing these results with the results of our larger study. We see a similar level of willingness to donate after participating in the Video First condition. This indicates that Hispanic individuals are just as willing to become organ donors as their non-Hispanic counterparts when provided with the necessary information and education about the donation process.

Moreover, most Hispanic participants who indicated a preference were inclined to register when the messaging emphasized the needs of others and originated from a relatable person rather than a public figure. This suggests that delivering the message and the message communicates are essential. Interestingly, there were no preferences for ethnicity or race. This may be because of the cited confusion among respondents, particularly among Hispanics, regarding the classification of ethnicity and race[35]. Specifically, although more participants reported that they did want the message to come from someone like them, they may not identify with the traditional concepts of race and ethnicity. Further, some Hispanics may identify with more than one race or ethnic category, therefore participants may not agree with the defined constructs by the federal administrative guidelines. Our findings also suggest that future interventions could be effectively implemented at the DMV, in primary care settings, or with a trusts and estate lawyer, especially when the messaging is tailored to sociocultural content.

***Limitations***

The study that served as the foundation for the current analysis concentrated more on participants’ intentions to give organs than on their actual registration as donors. The transtheoretical model, however, proposes that analyzing intention is a crucial first step in boosting donor registration rates[36]. Therefore, by examining how knowledge, motivations, and attitudes concerning organ donation change as a result of the intervention, we sought to address the first two stages of the model (awareness and reflection). A comparable video intervention should be studied in more detail to see how it affects actual donor registration rates. The use of an online poll in this study is another potential weakness. Although we used attention checks to guarantee data quality and contact a variety of potential donors in New York City, future studies should utilize alternate settings to replicate our findings.

**CONCLUSION**

Overall, disparities in organ donation among minority groups are a significant problem that needs to be addressed. Increasing awareness and understanding about organ donation in minority communities, improving access to healthcare, and increasing representation on organ transplant messaging materials are all steps that can help reduce these disparities and improve access to life-saving organ transplantation for minority communities.

**ARTICLE HIGHLIGHTS**

***Research background***

Research has documented barriers to organ donation, including: (1) Bodily integrity; (2) medical skepticism; (3) “ick”-discomfort toward the process; and (4) “jinx”-superstitions regarding preparations toward death. Furthermore, emotional video messaging is impactful in increasing the intention to register. While the emotional video messaging used in the present study was found to increase the intention to register among the Hispanic population.

***Research motivation***

Given the backdrop of shortages of organ donations and the benefits of a more diverse donor pool. In New York City (NYC), a place renowned for its diverse population, our goal was to evaluate the effects of a brief educational intervention meant to increase organ donation intentions. Additionally, we wanted to learn more about the attitudes and beliefs of Hispanic inhabitants of NYC toward organ donation as well as the predictors of it.

***Research objectives***

We hypothesized that an educational video addressing commonly cited barriers to organ donation would help ease resistance and change attitudes regarding intentions to donate.

***Research methods***

Data were collected using the online crowdsourcing platform CloudResearch targeting NYC residents. This study was approved by our Institutional IRB. Once consent was obtained and participants entered the survey, respondents were asked to report on demographic variables and their general impression of organ donation after death. Participants were then assigned at random to the video First condition, in which they saw a brief movie on organ donation before responding to the survey questions, or the Video Last condition, in which they answered the survey questions first and then watched the video. The five-minute intervention implemented was originally developed, tested, and found to significantly increase donation rates in a general population. The video presented a dialogue among twenty ethnically diverse individuals in terms of age and their experiences regarding organ donation, including donors, recipients, and loved ones of those who died while waiting for organ donation. Furthermore, the video has been found to elicit emotional responses and address concerns that are common barriers to donor registration.

***Research results***

Using a binomial logistic regression, the analysis provides information about the relationship between the effects of an emotive video and the intention to donate among Hispanic participants who were not already registered as donors. The willingness to go back and register was found to be significantly more probable for those who watched the emotive video before being asked about their organ donation opinions [OR: 2.05, 95%CI (1.06, 3.97)] (as presented in Table 3). Motivations for participation in organ donation were also captured in Table 4, with many stating the importance of messages coming from “people like me” and a message that highlights “the welfare of those in need”. Overall, the findings suggest that using an emotive video that addresses organ donation barriers to prompt organ donation intentions can be effective among the Hispanic populous. Future studies should explore using targeted messaging that resonates with specific cultural groups, highlighting the welfare of others.

***Research conclusions***

The wide variations in organ donation rates across the United States present both a problem and a chance. Our analysis has demonstrated that future campaigns must concentrate on densely populated, diversified locations with low donor rates if they are to boost organ donation registration. Educational initiatives that elicit strong emotions, address donor concerns, and take into account potential donors’ preferences must be conducted to increase the overall registration rate. By implementing these actions, we have the potential to significantly alter the situation and save the lives of thousands of people who pass away each year while awaiting organ transplants.

***Research perspectives***

Future research should examine how video intervention affects actual donor registration to have a more thorough understanding of its effects. Although we used attention checks to confirm the accuracy of the data, it is advised that future research replicate our findings in various contexts.

**REFERENCES**

1 **Health Resources and Services Administration**. Organ Donation Statistics. United States Department of Health & Human Services. Organ Donation Statistics. November 17, 2018. [cited 20 April 2023]. Available from: https://www.organdonor.gov/statistics-stories/statistics.html#glance

2 **Cardon JH**, Holbrook JC, Showalter MH. Estimating the effect of focused donor registration efforts on the number of organ donors. *PLoS One* 2020; **15**: e0241672 [PMID: 33147294 DOI: 10.1371/journal.pone.0241672]

3 **Grantham DA**. Transforming transplantation: The effect of the health and human services final rule on the organ allocation system. *USFL Rev* 2000; **35**: 751

4 **Duda L**. National organ allocation policy: the final rule. *Virtual Mentor* 2005; **7** [PMID: 23253588 DOI: 10.1001/virtualmentor.2005.7.9.hlaw1-0509]

5 **CenterState CEO**. Rate of registered organ donors grows, but state and regional rates still lag national rate. January 24, 2023. [cited 20 April 2023]. Available from: https://centerstateceo.com/news-events/rate-registered-organ-donors-grows-state-and-regional-rates-still-lag-national-rate

6 **Nowakowski B**. Colorado is Number One in the nation for highest donor designation rate (DDR). Donate Life Colorado. December 20, 2022. [cited 20 April 2023]. Available from: https://www.donatelifecolorado.org/blog/colorado-is-now-number-one-in-the-nation-for-highest-donor-designation-rate

7 **Register to Become an Organ and Tissue Donor Today**. New York State Donate Life Registry. January 24, 2023. [cited 20 April 2023]. Available from: https://donatelife.ny.gov/about-donation/

8 **Li AH**, Lo M, Crawshaw JE, Dunnett AJ, Naylor KL, Garg AX, Presseau J. Interventions for increasing solid organ donor registration. *Cochrane Database Syst Rev* 2021; **4**: CD10829 [PMID: 35608942 DOI: 10.1002/14651858.CD010829.pub2]

9 **Donate Life America**. Does Race Matter in Organ Donation and Transplant? August 2, 2022. [cited 20 April 2023]. Available from: https://www.donatelife.net/race-ethnicity-and-donation/

10 **HHS gov**.Office of Minority Health (no date) Home Page-Office of Minority Health (OMH). December 13, 2022. [cited 20 April 2023]. Available from: https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4

11 **United States Census Bureau**. QuickFacts: United States. June 22, 2020. [cited 20 April 2023]. Available from: https://www.census.gov/quickfacts/NY

12 **Kernodle AB**, Zhang W, Motter JD, Doby B, Liyanage L, Garonzik-Wang J, Jackson KR, Boyarsky BJ, Massie AB, Purnell TS, Segev DL. Examination of Racial and Ethnic Differences in Deceased Organ Donation Ratio Over Time in the US. *JAMA Surg* 2021; **156**: e207083 [PMID: 33566079 DOI: 10.1001/jamasurg.2020.7083]

13 **Alvarado F**, Cervantes CE, Crews DC, Blanck J, Al Ammary F, Ng DK, Purnell TS. Examining post-donation outcomes in Hispanic/Latinx living kidney donors in the United States: A systematic review. *Am J Transplant* 2022; **22**: 1737-1753 [PMID: 35258164 DOI: 10.1111/ajt.17017]

14 **Desai N**, Lora CM, Lash JP, Ricardo AC. CKD and ESRD in US Hispanics. *Am J Kidney Dis* 2019; **73**: 102-111 [PMID: 29661541 DOI: 10.1053/j.ajkd.2018.02.354]

15 **Hall YN**. Social Determinants of Health: Addressing Unmet Needs in Nephrology. *Am J Kidney Dis* 2018; **72**: 582-591 [PMID: 29548780 DOI: 10.1053/j.ajkd.2017.12.016]

16 **Crews DC**, Liu Y, Boulware LE. Disparities in the burden, outcomes, and care of chronic kidney disease. *Curr Opin Nephrol Hypertens* 2014; **23**: 298-305 [PMID: 24662984 DOI: 10.1097/01.mnh.0000444822.25991.f6]

17 **Aguayo-Mazzucato C**, Diaque P, Hernandez S, Rosas S, Kostic A, Caballero AE. Understanding the growing epidemic of type 2 diabetes in the Hispanic population living in the United States. *Diabetes Metab Res Rev* 2019; **35**: e3097 [PMID: 30445663 DOI: 10.1002/dmrr.3097]

18 **Centers for Disease Control and Prevention**. National Diabetes Statistics Report, 2020. Centers for Disease Control and Prevention, United States Dept of Health and Human Services; 2020. October 5, 2021. [cited 20 April 2023]. Available from: https://www.cdc.gov/diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf

19 **U.S. Department of Health and Human Services**. USRD System 2020 USRDS Annual Data Report: epidemiology of kidney disease in the United States. 2020. [cited 20 April 2023]. Available from: https://adr.usrds.org/2020

20 **AlRuthia Y**, Sales I, Almalag H, Alwhaibi M, Almosabhi L, Albassam AA, Alharbi FA, Bashatah A, Asiri Y. The Relationship Between Health-Related Quality of Life and Trust in Primary Care Physicians Among Patients with Diabetes. *Clin Epidemiol* 2020; **12**: 143-151 [PMID: 32104098 DOI: 10.2147/CLEP.S236952]

21 **Alpers LM**. Distrust and patients in intercultural healthcare: A qualitative interview study. *Nurs Ethics* 2018; **25**: 313-323 [PMID: 27284017 DOI: 10.1177/0969733016652449]

22 **Berry LL**, Parish JT, Janakiraman R, Ogburn-Russell L, Couchman GR, Rayburn WL, Grisel J. Patients’ commitment to their primary physician and why it matters. *Ann Fam Med* 2008; **6**: 6-13 [PMID: 18195309 DOI: 10.1370/afm.757]

23 **Nutbeam D**. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promot Int* 2000; **15**: 267 [DOI: 10.1093/heapro/15.3.259]

24 **Berkman ND**, Davis TC, McCormack L. Health literacy: what is it? *J Health Commun* 2010; **15** Suppl 2: 9-19 [PMID: 20845189 DOI: 10.1080/10810730.2010.499985]

25 **Hälleberg Nyman M**, Nilsson U, Dahlberg K, Jaensson M. Association Between Functional Health Literacy and Postoperative Recovery, Health Care Contacts, and Health-Related Quality of Life Among Patients Undergoing Day Surgery: Secondary Analysis of a Randomized Clinical Trial. *JAMA Surg* 2018; **153**: 738-745 [PMID: 29710226 DOI: 10.1001/jamasurg.2018.0672]

26 **Sewell AA**. Inequality: Live poor, die young. *Nature* 2017; **18**; 545: 286-287 [DOI: 10.1038/545286a]

27 **Gordon EJ**, Shand J, Black A. Google analytics of a pilot mass and social media campaign targeting Hispanics about living kidney donation. *Internet Interv* 2016; **6**: 40-49 [PMID: 30135813 DOI: 10.1016/j.invent.2016.09.002]

28 **Murphy MD**, Pinheiro D, Iyengar R, Lim G, Menezes R, Cadeiras M. A Data-Driven Social Network Intervention for Improving Organ Donation Awareness Among Minorities: Analysis and Optimization of a Cross-Sectional Study. *J Med Internet Res* 2020; **22**: e14605 [PMID: 31934867 DOI: 10.2196/14605]

29 **English V**. Is presumed consent the answer to organ shortages? Yes. *BMJ* 2007; **334**: 1088 [PMID: 17525449 DOI: 10.1136/bmj.39199.475301.AD]

30 **Wright L**. Is presumed consent the answer to organ shortages? No. *BMJ* 2007; **334**: 1089 [PMID: 17525450 DOI: 10.1136/bmj.39199.492894.AD]

31 **Coppen R**, Friele RD, Marquet RL, Gevers SK. Opting-out systems: no guarantee for higher donation rates. *Transpl Int* 2005; **18**: 1275-1279 [PMID: 16221158 DOI: 10.1111/j.1432-2277.2005.00202.x]

32 **Rithalia A**, McDaid C, Suekarran S, Myers L, Sowden A. Impact of presumed consent for organ donation on donation rates: a systematic review. *BMJ* 2009; **338**: a3162 [PMID: 19147479 DOI: 10.1136/bmj.a3162]

33 **Molmenti EP**, Finuf KD, Patel VH, Molmenti CL, Thornton D, Pekmezaris R. A Randomized Intervention to Assess the Effectiveness of an Educational Video on Organ Donation Intent. *Kidney360* 2021; **2**: 1625-1632 [PMID: 35372974 DOI: 10.34067/KID.0001392021]

34 **Thornton JD**, Alejandro-Rodriguez M, León JB, Albert JM, Baldeon EL, De Jesus LM, Gallardo A, Hossain S, Perez EA, Martin JY, Lasalvia S, Wong KA, Allen MD, Robinson M, Heald C, Bowen G, Sehgal AR. Effect of an iPod video intervention on consent to donate organs: a randomized trial. *Ann Intern Med* 2012; **156**: 483-490 [PMID: 22473435 DOI: 10.7326/0003-4819-156-7-201204030-00004]

35 **Smith FD**, Woo M, Austin SB. 'I didn't feel like any of those things were me': results of a qualitative pilot study of race/ethnicity survey items with minority ethnic adolescents in the USA. *Ethn Health* 2010; **15**: 621-638 [PMID: 20799118 DOI: 10.1080/13557858.2010.503872]

36 **Prochaska JO**, Velicer WF. The transtheoretical model of health behavior change. *Am J Health Promot* 1997; **12**: 38-48 [PMID: 10170434 DOI: 10.4278/0890-1171-12.1.38]

**Footnotes**

**Institutional review board statement:** The study was reviewed and approved by the Institutional Review Board at Northwell Health (Approval No. 19-0009).

**Informed consent statement:** All study participants, or their legal guardians, provided informed written consent before study enrollment.

**Conflict-of-interest statement:** The authors declare that they have no conflict of interest.

**Data sharing statement:** The data used in this study will be made available upon request to qualified researchers for the purposes of reproducing the results or for further analysis.

**STROBE statement:** The authors have read the STROBE Statement—a checklist of items, and the manuscript was prepared and revised according to the STROBE Statement—a checklist of items.

**Open-Access:** This article is an open-access article that was selected by an in-house editor and fully peer-reviewed by external reviewers. It is distributed in accordance with the Creative Commons Attribution NonCommercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: https://creativecommons.org/Licenses/by-nc/4.0/

**Provenance and peer review:** Unsolicited article; Externally peer reviewed.

**Peer-review model:** Single blind

**Peer-review started:** March 2, 2023

**First decision:** April 13, 2023

**Article in press:**

**Specialty type:** Transplantation

**Country/Territory of origin:** United States

**Peer-review report’s scientific quality classification**

Grade A (Excellent): A

Grade B (Very good): B

Grade C (Good): C

Grade D (Fair): 0

Grade E (Poor): 0

**P-Reviewer:** Eseadi C, Nigeria; Mikulic D, Croatia **S-Editor:** Chen YL **L-Editor:** A **P-Editor:** Chen YL

**Table 1 Methodology**

|  |  |  |
| --- | --- | --- |
|  | **Video first condition** | **Video last condition** |
| Participants | 192 | 173 |
| IV | 5 min 25 s emotive video addressing common barriers to organ donation | |
| DV | An 85-item Redcap survey measured participant demographics, attitudes, and knowledge of organ donation as well as intention to register as an organ donor | |
| Procedure | A human intelligence task, informed consent was required, random assignment was implemented | |

**Table 2 Hispanic participant characteristics and test of proportions, *n* (%)**

|  |  |  |  |
| --- | --- | --- | --- |
| **Total (*n* = 365)** | | **(*n* = 1905)** | |
| **Registered (*n* = 137)** | **Not registered (*n* = 228)** |
| Gender |  |  |  |
| Female | 236 (65) | 87 (37) | 149 (63) |
| Male | 126 (34) | 48 (38) | 78 (62) |
| Other/prefer not to say | 3 (1) | 2 (67) | 1 (33) |
| Age (yr) |  |  |  |
| ≤ 39 | 263 (72) | 105 (40) | 158 (60) |
| 40-69 | 97 (27) | 31 (32) | 66 (68) |
| ≥ 70 | 5 (1) | 1 (20) | 4 (80) |
| Race |  |  |  |
| White/Caucasian | 130 (36) | 60 (46) | 70 (54) |
| Black/African American | 54 (15) | 20 (37) | 34 (63) |
| Asian | 4 (1) | 3 (75) | 1 (25) |
| Multiracial | 63 (17) | 23 (37) | 40 (63) |
| Other | 101 (28) | 29 (29) | 72 (71) |
| Native American or Alaskan Native | 5 (1) | 1 (20) | 4 (80) |
| Native Hawaiian or Other Pacific, Islander | 3 (1) | 0 | 3 (100) |
| Prefer not to say | 5 (1) | 1 (20) | 4 (80) |
| Spirituality |  |  |  |
| Yes | 252 (69) | 106 (42) | 146 (58) |
| No | 99(27) | 28 (28) | 71 (72) |
| Prefer not to say | 14 (4) | 3 (21) | 11 (79) |
| Religiosity |  |  |  |
| Yes | 162 (44) | 64 (40) | 98 (60) |
| No | 189 (52) | 70 (37) | 119 (63) |
| Prefer not to say | 14 (4) | 3 (21) | 11 (79) |
| Religious denomination |  |  |  |
| Christian | 198 (54) | 77 (39) | 121 (61) |
| Jewish | 3 (1) | 2 (67) | 1 (33) |
| Muslim | 6(2) | 3 (50) | 3 (50) |
| Buddhist | 2 (1) | 2 (100) | 0 |
| Non-religious | 103 (28) | 41 (40) | 62 (60) |
| Other | 41 (11) | 10 (24) | 31 (76) |
| Prefer not to say | 12 (3) | 2 (17) | 10 (83) |
| Marital status |  |  |  |
| Single/never married | 219 (60) | 77 (35) | 142 (65) |
| Married/living as married | 123 (34) | 52 (42) | 71 (58) |
| Divorced/separated | 17 (5) | 6 (35) | 11 (65) |
| Widowed | 4 (1) | 1 (25) | 3 (75) |
| Prefer not to say | 2 (1) | 1 (50) | 1 (50) |
| Level of education |  |  |  |
| 2-yr associate degree or less | 216 (59) | 63 (29) | 153 (71) |
| 4-yr college degree (*e.g.*, Bachelor) | 121 (33) | 56 (46) | 65 (54) |
| Graduate degree (*e.g.*, Master, MD, PhD) | 28 (8) | 18 (64) | 10 (36) |
| Employment status |  |  |  |
| Full time or part time | 182 (50) | 86 (47) | 96 (53) |
| Unemployed | 116 (32) | 33 (28) | 83 (72) |
| Prefer not to say | 4 (1) | 0 | 4 (100) |
| Self-employed |  |  |  |
| Yes, *n* (%) | 59 (16) | 28 (47) | 31 (53) |
| No, *n* (%) | 306 (84) | 109 (36) | 197 (64) |
| Annual income |  |  |  |
| < $30000 | 108 (30) | 33 (31) | 75 (69) |
| $30001-$60000 | 113 (31) | 41 (36) | 72 (64) |
| $60001-$100000 | 88 (24) | 43 (49) | 45 (51) |
| > $100000 | 36 (10) | 19 (53) | 17 (47) |
| Prefer not to say | 20 (5) | 1 (5) | 19 (95) |
| Insurance |  |  |  |
| Medicaid or Medicare | 167 (46) | 43 (26) | 124 (74) |
| Employer | 139 (38) | 71 (51) | 68 (49) |
|  | 27 (7) | 15 (56) | 12 (44) |
| Out of pocket |  |  |  |
| Other | 15 (4) | 5 (33) | 10 (67) |
| Prefer not to say | 15 (4) | 2 (13) | 13 (87) |

Fifty participants did not indicate their registration status.

**Table 3 Effects of the video among Hispanic participants not registered as organ donors**

|  |  |  |  |
| --- | --- | --- | --- |
| **OR** |  | **95%CI** | ***P* value** |
| Outcome |  |  |  |
| Willingness to go back | 2.05 | 1.06, 3.97 | 0.03 |
| Factors associated with OD |  |  |  |
| Religious beliefs | 1.54 | 0.64, 3.72 | 0.34 |
| Bodily integrity | 0.89 | 0.50, 1.58 | 0.69 |
| Impact funeral proceedings | 0.89 | 0.46, 1.72 | 0.72 |
| Treated differently by doctor | 1.03 | 0.60, 1.77 | 0.91 |
| Recipient | 0.89 | 0.49, 1.62 | 0.70 |
| Ick factor | 1.65 | 0.82, 3.32 | 0.16 |
| Jinx factor | 0.82 | 0.48, 1.40 | 0.47 |
| Health of donor | 0.53 | 0.31, 0.90 | 0.02 |
| Age limit of donor | 0.79 | 0.47, 1.34 | 0.38 |
| Treated differently by race | 0.58 | 0.31, 1.11 | 0.10 |
| Notify relatives | 1.13 | 0.60, 2.10 | 0.71 |
| Association with pain | 0.58 | 0.22, 1.55 | 0.28 |
| Legal to buy an organ | 0.60 | 0.33, 1.12 | 0.11 |
| Known where to sign up | 1.11 | 0.66, 1.86 | 0.70 |
| Know process to sign up | 1.08 | 0.62, 1.85 | 0.79 |
| Know can sign up at DMV | 2.21 | 1.22, 4.03 | 0.01 |
| Know can sign up on online | 0.97 | 0.55, 1.71 | 0.91 |
| Appropriate to be asked at DMV | 0.74 | 0.43, 1.25 | 0.26 |
| Receive compensation | 1.09 | 0.62, 1.92 | 0.76 |
| Receive funeral payment | 1.02 | 0.60, 1.72 | 0.10 |
| Opt-out system | 0.49 | 0.25, 0.96 | 0.04 |

“OR” represents odds of selecting “Yes” to respective question for those in the Video First condition compared to those in the Video Last condition. OR: Odds ratio; CI: Confidence interval; DMV: Department of motor vehicle.

**Table 4 Motives for organ donation among Hispanics, *n* (%)**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Total (*n* = 365)** | | | **Registered organ donor (*n* = 137)** | | | **Not registered organ donor (*n* = 228)** | | |
| **Yes** | **No** | **Doesn’t matter** | **Yes** | **No** | **Doesn’t matter** | **Yes** | **No** | **Doesn’t matter** |
| Receiving message from |  |  |  |  |  |  |  |  |  |
| Someone like you | 127 (35) | 40 (11) | 198 (54) | 43 (31) | 16 (12) | 78 (57) | 84 (37) | 24 (11) | 120 (53) |
| Same gender as you? | 44 (12) | 65 (18) | 256 (70) | 17 (12) | 27 (20) | 93 (68) | 27 (12) | 38 (17) | 163 (71) |
| Same race as you? | 45 (12) | 64 (18) | 256 (70) | 19 (14) | 27 (20) | 91 (66) | 26 (11) | 37 (16) | 165 (72) |
| Your community? | 53 (14) | 61 (17) | 251 (69) | 29 (21) | 25 (18) | 83 (61) | 24 (11) | 36 (16) | 168 (74) |
| Economic status as you? | 59 (16) | 66 (18) | 240 (66) | 28 (20) | 25 (18) | 84 (61) | 31 (14) | 41 (18) | 156 (68) |
| Own ethnic background? | 44 (12) | 66 (18) | 255 (70) | 15 (11) | 29 (21) | 93 (68) | 29 (13) | 37 (16) | 162 (71) |
| Message of those in need? | 139 (38) | 60 (16) | 166 (46) | 50 (36) | 23 (17) | 64 (47) | 89 (39) | 37 (16) | 102 (45) |
| A public figure? | 38 (10) | 90 (25) | 237 (65) | 17 (12) | 35 (26) | 85 (62) | 21 (9) | 55 (24) | 152 (67) |
| Motivated by hearing from |  |  |  |  |  |  |  |  |  |
| Relatives of organ donor | 214 (56) | - | - | 94 (44) | - | - | 120 (56) |  |  |
| Recipient of organ donation | 183 (48) | - | - | 82 (45) | - | - | 101 (55) |  |  |
| Family of recipient who died waiting | 209 (55) | - | - | 81 (39) | - | - | 128 (61) |  |  |
| Physician or provider | 120 (32) | - | - | 61 (51) | - | - | 59 (49) |  |  |
| Other | 10 (3) |  |  | 5 (50) | - | - | 5 (50) |  |  |

Frequency of responses regarding motivation to participation in an organ donor program.