The Organ Shortage Crisis: Analyzing MA Perspectives and Considering Future Donation Legislation

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ABSTRACT

Public awareness and opinions on organ donation, as well as donation-related topics, are factors that contribute to a population’s organ donation rate. Considering the growing global organ shortage, assessing these factors and finding areas of improvement for donation education and publicly supported paths to approaching the issue is critical. The aim of this study was to collect and evaluate the knowledge and opinions of Massachusetts residents on organ donation and related topics. This was done using an online survey questionnaire with a total of 100 valid responses. This study concluded that the promotion of organ donation in the United States should primarily place focus on increased donation education campaigns, for both the general public and within the K-12 curriculum. Also, plan to move toward presumed consent, and not financial incentives, while the world waits for scientific advances, such as the development of synthetic organs, to be further researched.

Introduction

Context

Healthy organs are a necessity for life, and thanks to past scientific and medical developments surrounding organ and tissue donation, individuals who otherwise might not have had a chance at life were able to find one through receiving the healthy organs or tissues of a donor. Over the past few decades, however, it has been increasingly challenging for many of these individuals to find viable organs due to an issue referred to as the organ shortage crisis, where the supply of organs is much lower than the demand.

Due to this problem, according to the United States HHS, every 9 minutes another person is added to the transplant waiting list and daily, about 20 people in the country die waiting for an organ transplant (United States Department of Health and Human Services). This growth in demand for organs is partly due to the rapidly changing demographics of the country, such as how life expectancy is longer and people therefore have a higher chance of organ failure caused by common comorbidities such as cancer, diabetes, hypertension, kidney disease, or cardiovascular disease generally associated with older age (Health Resources and Services Administration, 2020). In the United States specifically, this gap between the supply and demand of transplantable organs continues to widen significantly, even despite many public outreach campaigns intended to promote donor registration (Shapiro, A. K., & DePergola II, P. A., 2020). According to a survey conducted by Donate Life America, a nonprofit organization that promotes donor registration in the United States, 95% of surveyed Americans are in favor of being a donor, but only about 58% of those Americans are actually registered to donate. This statistic may be shocking, and is the reason why, whether it be methods such as education to disprove misconceptions, or policies like presumed consent to make the registration process more streamlined, there must be new methods employed to expand the donor pool to keep up with this growing need for organs.

In the United States itself, this crisis has stripped thousands of patients of achieving a basic quality of life, resulting in a significant increase in the use of alternative medical care, such as dialysis, a treatment for
those in kidney failure still waiting for an available organ (Böhlke M, 2012). Additionally, the effects of the SARS-CoV-2 virus outbreak have rippled into nearly all facets of healthcare, including organ donation, and so the issue of the organ shortage crisis has been exacerbated even further since early 2020 (Penn Medicine, 2020). While this fact is not surprising, it serves as a call to action in the way that this issue is continually getting worse, yet there is still not much being said or done about it, except by very select groups of individuals in scientific and medical communities.

This rapidly growing shortage has resulted in a need to find both practical and efficient ways to approach the issue by finding more people willing to donate. Whether that be through beginning educational programs for the general public, moving toward presumed consent, creating a priority allocation system, or pursuing a combination of different strategies, it is agreed upon that something must be done. Still, for changes like these to be made into real initiatives, there must first be an understanding of how the public might react to certain options. The intention of this study is to do just that, and the researcher will be gathering data reflecting the existing organ donation knowledge and opinions of those living in the state of Massachusetts.

**Literature Review**

**Search Strategies**

Sources were located by searching various databases with the advanced search settings set to “peer-reviewed” to ensure credibility. Some keywords used while researching include: organ donation, organ shortage crisis, solutions, public opinion, surveys, interviews, presumed consent, education, financial incentives, and priority allocation.

**Education**

One of the methods currently being proposed is implementing new education initiatives for both the general public and for students in K-12. This education would focus on educating individuals on the necessity of donation as well as work to dispel any commonly held donation myths (Abouna GM, 2008). Increasing organ donation education is one of the more straightforward approaches to this issue, and is accepted nearly across the board, as improving education is not commonly seen as something that is debatable. Specific to K-12 education, a study done in Canada concluded that their adolescent classroom organ donation education initiatives were promising in increasing public support of organ donation (Li, A. H., et al., 2013), which could be beneficial in approaching the shortage crisis if enacted in the United States, perhaps in the health curriculum. Moreover, such initiatives have the potential to lead to an increase in knowledge among the student’s family members and loved ones as well, as seen in a Netherlands primary school teaching module (Siebelink, M. J., et al., 2017), therefore making K-12 initiatives all the more worthwhile. In addition to K-12, more general public education initiatives could limit much of the fear some adults still have around organ donation, as much of that is based on myth, misinformation, and medical mistrust. One effective way of debunking these myths has been through entertainment, such as television or live shows. A study done in Germany used this entertainment-based intervention and saw a significant increase in the willingness to donate organs in the intervention groups (Heitland, et al., 2020). The researcher proposes that respondents in Massachusetts will be open to further organ donation education, as the method is not commonly seen as invasive or forceful. This study will also, in addition to gauging opinions on certain topics, tries to further understand the need for education by asking knowledge-based questions. Still, making any such changes would not solve the shortage completely, and may have to be implemented in tandem with another strategy, or strategies, in order to be effective.
Presumed Consent

Another possible strategy that is considered more controversial is the introduction of a presumed consent policy, also known as an opt-out policy, as opposed to the current opt-in policy found in the United States. Introducing a presumed consent policy would mean that, rather than having to indicate that one is a donor, one would have to indicate that they are not. This would change the legal assumption to be that one is a donor unless otherwise expressed, rather than the current assumption being that one is not a donor unless otherwise expressed (English, V., & Wright, L., 2007). The idea is that this will result in more total registered donors, as it has been proved to do so in other countries where opt-out laws result in donation rates 25 to 50% higher than those in countries requiring explicit consent (Abadie & Gay, 2006), however there are some recorded disagreements over this proposal in current literature. Some heavily favor opt-out, such as with Carl Cohen from the University of Michigan School of Medicine, who states that the current system is “wrong because the bulk of people in the United States would like to donate their organs, but the present system is inconsistent with that.” The system the United States has now, opt-in, instead aligns with the belief that no one wishes to donate their organs for transplantation, and “therefore [it] doesn’t protect the autonomy of the decedents” (Cohen, 1992). Others do not favor opt-out, such as Dr. Segev, a professor of surgery at Johns Hopkins University School of Medicine who states that such a policy may “challenge the relationship between the transplant community and the general public,” which he argues should be mutually supportive. Rather than forcing people to donate their relatives’ organs if they fail to opt-out before death, he says “we need to foster more awareness of transplantation and transplant issues to procure more organs for life saving transplants,” meaning efforts should be focused more on education (Segev et al., 2011). Because of these many disagreements surrounding presumed consent by experts in the field, the goal of this study is to get a preliminary understanding and gauge how everyday citizens may feel about proposals such as this.

Incentives

Similarly, there are also current disputes over incentive methods to donate such as priority allocation and financial incentives. Priority allocation is a method that would introduce what is referred to as a priority system, in which previously registered donors receive a preferred status in the allocation of organs for transplant ahead of those who have not registered (Shapiro, A. K., & DePergola II, P. A., 2020). Financial incentives in regard to organ donation would mean that there could be potential for rewards for registering such as tax breaks, discounted driver’s license fees, and reimbursement for medical expenses if you are a donor (Harris, C. E., & Alcorn, S. P., 2001). Many argue that incentives such as these would be effective in increasing donation rates, whereas others reason it is a system that might be taken advantage of (Chandler, et al., 2012). These two options are both heavily debated in their literature, and so the researcher anticipates seeing similar trends when surveying those in Massachusetts.

Gap in Research

From these many possible options, it is important to be able to identify which one/s may be the most realistic to look further into, advocate for, and pursue before this shortage further worsens and more die because of it. To do so, this research will be looking at Massachusetts residents and their background knowledge on the issue, potentially hinting toward a need for education initiatives, as well as their opinions on the aforementioned options.

Pre-existing research regarding awareness on organ donation and public opinion on solutions to the organ shortage crisis exists, such as in Morocco (El Hangouche et al., 2018), however no research in this field has been done in Massachusetts, or in the United States for that matter. Another pre-existing study is one done
in the United Kingdom, a study that focused on comparing individuals with specific “life experience,” which will be replicated in this study (Schicktanz, S., & Schweda, M., 2009). Due to this, this research will be adding onto those previous studies and fill a research gap, therefore contributing to the body of knowledge.

This research will take place in the state of Massachusetts, rather than the United States as a whole, to maintain feasibility and potential value, as this type of research will likely be of more value at the state rather than national level. Ideally, this research will help to identify what the next steps should be in approaching the organ shortage crisis, and even if those next steps are on the state level to begin with, the ideas still have potential to expand to other states, then nationally if proven to be effective. To fill this geographic gap in research, the guiding research question for this study is: in accordance with data collected from Massachusetts residents, what should the next steps be to increase the organ donor pool in the state and/or country?

The researcher, upon exploring the field’s body of knowledge, hypothesizes that this study will expose a need for further organ donation education, develop an understanding of how Massachusetts residents feel about donation and related issues, and also reach a clear conclusion on what organ shortage crisis related policy, or policies, would be most popular with those in MA while the world waits for more research and scientific advances in areas such as porcine stem cell generation and three-dimensional printing, two methods being looked into for growing synthetic organs (University of Maryland, 2020).

**Research Design and Methodology**

**Synopsis of Study Design**

The researcher took a mixed method approach by distributing a survey and conducting online interviews. This study explores the prior knowledge and opinions of Massachusetts residents on topics surrounding organ donation and potential approaches to address the organ shortage crisis. To do this, a state-wide cross-sectional survey was conducted between December 2020 and April 2021 throughout the state of Massachusetts. Additionally, to better understand these survey responses on a more individual level, the researcher reached out directly to healthcare professionals, organ donors and their loved ones, as well as organ recipients and their loved ones in the state of Massachusetts.

This study was designed with feasibility and potential future value in mind, therefore the researcher decided that a national cross-sectional survey encompassing the entirety of the United States would not be an ideal option. This is because, with regard to feasibility, the researcher would have to ensure that there were enough respondents from each of the fifty states, with each providing enough survey responses so that the results were not skewed for that particular state. Conducting state-wide research in only Massachusetts, however, made it so that the researcher was only concerned with getting enough responses from the different regions of the state. Doing this made the research much more practical and also better reflective of a particular group’s perspective on an issue, those in a specific state, rather than ending up with a broad country-wide generalization. Additionally, choosing to follow through with this state-wide approach also increases its potential value for the future. Having state-specific information detailing informedness and opinions on organ donation is much more valuable than broader, national information on those same things. When thinking about the future of organ donation legislation, it is very likely that it will first occur on a state rather than national level. For this reason, it makes the most sense to collect state information that reflects the people of that state, which can then be used to first push for local policy and gain traction, as opposed to starting out on the national stage and having limited opportunity for success in approaching the issue.

**Subjects**
The subjects of this study are minors and adults residing in the state of Massachusetts. While this study could have focused only on adult respondents, the researcher decided to include minors too. Choosing to include minors serves a purpose, as many of these individuals likely have the same perspective on organ donation that they will have as an adult. Many of them will also stay in the state once they graduate high school, as nearly six in ten Americans (58.5 percent) currently reside in the state where they were born (Bloomberg CityLab, 2019). Therefore, the intent they have in the future for donation, how much they currently know about the issue, and their opinions on donation topics are equally significant and important to understand, too.

In the survey questionnaire the researcher asked respondents to indicate whether they or a loved one have received an organ or tissue transplant, whether they or a loved one have donated an organ or tissue, and whether they are or have been a healthcare professional. If any of those three questions applied to the respondent, they were placed into the “affected” group, which is a pool of respondents considered to be directly impacted by donation. The rest of the respondents to the survey were considered to be in the “unaffected” group, who are not directly impacted by donation. The responses of these two groups were then relocated to new spreadsheets and analyzed separately. The purpose of this was to help the researcher better understand the collected data. It is very possible that the opinions and background knowledge of these two groups greatly differ, and because of this, the “affected” and “unaffected” responses were analyzed separately to help the researcher reach a more accurate conclusion.

Survey Questionnaire

The questionnaire in this study was partially inspired by the cross-sectional survey done in Morocco, which, likewise, was intended to evaluate the knowledge and perception toward organ donation (El Hangouche, A. J., et al., 2018). Similar to the Moroccan study, the survey questionnaire for this research was divided into four main parts. The first being the consent section, where if the respondent selected that they “did not consent,” the survey was ended for them. The second section was the demographic portion, where the researcher collected basic socio demographic profiles of the respondents and ensured that they are in fact residing in the state of Massachusetts. If the respondent answered that “no,” they do not live in the state, the survey ended for them. The third section looked to understand the respondent’s basic stance on organ donation and whether or not they are a healthcare worker, an organ donor or a loved one of a donor, or an organ recipient or a loved one of a recipient, which would determine whether they would be in the “affected” or “unaffected” group. For the purpose of this study, the term “loved one” will refer to anyone with a close relationship to a donor or recipient, whether that be through friendship, companionship, or familial relatedness. Finally, the fourth section introduced and defined various organ donation related topics including the organ shortage crisis, presumed consent, priority allocation, and financial incentives. Then, the survey requested the respondent’s opinion on the topic, asked the respondent if they had heard of that term before, and provided the option for the respondent to elaborate on their answers with a long-answer response box.

This survey, overall, consisted of an informed consent portion, five demographic questions, seven experience and background information questions, twelve opinion questions, and six open-ended qualitative questions, all of which were approved by the Institutional Review Board (IRB00012841 Norwood High School IRB #1) at the researcher’s high school. The questions were added to a Google Form and distributed from there via email. The responses were then recorded in a Google Sheet. All of the surveys were filled out anonymously after obtaining an informed consent from each survey participant.

Interviews
The interviews in this study were conducted online and over email. The subjects for these interviews were individuals who were in the “affected group.” The questions in the interview section were subjective and designed to understand how donation has affected the lives of these individuals, whether that be directly or indirectly. Because the majority of these respondents have a lot of knowledge in the field, they were asked to go into detail about which approaches to the organ shortage crisis they think would be the most and least effective. They were also asked to elaborate if their life circumstances have changed their view of donation, whether there are misconceptions that they’re aware of, and if they feel the public knows enough about donation and needs increased education on the issue.

Delimitations

Delimitations were established ahead of time in order to ensure the subject pool aligned with the research goal. First, only schools, organ recipient and organ donor support groups, and hospitals located in the state of Massachusetts were contacted as participants in the survey. Any survey response submitted outside of the state was excluded. Second, all individuals requested to respond to the online interview questions all resided in Massachusetts as well, any from out of state were omitted.

Results

Data Review Process

Once the data collecting period ended, the researcher organized all responses into Google Sheets. Three spreadsheets were made, one with all responses, one with “affected” group responses, and one with “unaffected” group responses. The purpose of doing this was so that the researcher could draw more specific conclusions from the data. The researcher made graphs for each question on each of the sheets and compared them to one another. Questions that had very split results were not considered to be useful, but if the results leaned significantly a certain way or there was a notable difference between the responses between the “affected” and “unaffected” groups, the researcher considered that data as notable and drew conclusions from it.

Findings

To begin with the very basic information that was collected from the survey, all 104 respondents consented to their participation (figure 1). Of these 104 people, 4 indicated that they were from outside of Massachusetts, and since this study took place only in the state, their responses were discarded (figure 2).

Figure 1. Consent to participate in survey
Next, the researcher found that 77% of all respondents are donors (figure 3). This number is very high in comparison to the actual organ donation rate in the state of Massachusetts, which is only about 50% according to Donate Life America (2013). Additionally, 11% indicated that they would be donors if they knew how to be, a statistic that shows a need for further education campaigns informing people how to register.

Then, the researcher defined the term “Organ Shortage Crisis” for respondents and asked them to rank how serious they viewed the problem. A vast majority ranked it as a 4 or 5, meaning that most viewed it as very serious (figure 4). Some interview responses asking respondents to elaborate on their previous answer to this question mention them knowing people directly affected by this issue or being directly impacted by it themselves. Examples of this include, “I feel like my sister shouldn’t have waited for six years for a kidney” and “I know of someone who passed away while waiting for an organ transplant” (figure 5). After that, the survey asked respondents if they had heard of the issue prior, and when looking at these results the researcher looked at the “affected” versus “unaffected” groups. The “affected” being organ donors and recipients, their loved ones, and healthcare workers. “Unaffected” meaning none of those apply. As predicted, the researcher found that much more of the “affected” group had heard of the term before (figure 6 A & B). The 16% knowledge difference shows a discrepancy between those whose lives are directly affected by donation and those whose aren’t, another reason for further organ donation education and awareness.
Figure 4. Survey responses to “please rank how you view the severity of the organ shortage crisis” ranging from 1 (not serious) to 5 (very serious)

Figure 5. Qualitative opinions of respondents on the severity of the organ shortage crisis

“There is obviously a need that is not being met and people are either having shorter lives or a lower standard of living because of it” (4)
“I feel like my sister shouldn’t have waited for six years for a kidney” (5)
“I know of someone who passed away while waiting for an organ transplant” (4)
“We are living in a pandemic. If you asked this question pre-COVID I think people would answer differently” (2)
“I know several people who passed away while waiting for a transplant, it is very serious, something should be done” (5)
“I’m grateful to have been lucky enough to get a liver transplant. My wait on the transplant list was 6 months” (5)

Figure 6. A. Affected group survey responses to “had you heard of the organ shortage crisis prior to taking this survey?” B. Unaffected group survey responses to “had you heard of the organ shortage crisis prior to taking this survey?”

Following that, the researcher then informed respondents about potentially teaching students about organ donation in K-12 health classes. The survey asked how open they would be to this, and most of the respondents agreed on being relatively open. There was a significant amount of 3, 4, and 5 responses (figure
This makes K-12 donation education a contender for the future, as there weren’t very many who disapproved of it, however there was a lot of apprehension. This can be seen in some qualitative remarks reflecting on the question, such as how it might be “difficult to handle” for young kids or “would require a delicate approach” (figure 8). Many were open to it though, expressing that it “is a great starting point for educating people about organ donation” and “should be part of the health curriculum” (figure 8). Finally, the researcher asked if respondents had heard of K-12 education proposals before, and again found that the affected group had more background knowledge, although this time it wasn’t as large of a gap between the two groups (figure 9 A & B).

Figure 7. Survey responses to “please indicate your openness to introducing increased organ donation education into the K-12 curriculum” ranging from 1 (not at all open) to 5 (very open)

Figure 8. Qualitative opinions of respondents on increasing organ donation education in the K-12 curriculum

Figure 9. A. Affected group survey responses to “had you heard of potentially introducing increased K-12 donation education before this survey?” B. Unaffected group survey responses to “had you heard of potentially introducing increased K-12 donation education before this survey?”
Next, the researcher introduced presumed consent, which was defined as a policy that would make it so that, rather than having to indicate that you are a donor, you would have to indicate that you are not-opting out as opposed to the current opt-in. Respondents were asked to rank how open they were to seeing presumed consent be implemented, from 1, not at all open, to 5, very open. The responses were in favor of presumed consent with there being many 4 and 5 responses, and so it is also a strong contender for the future (figure 10). Some interview responses vitally mention, if presumed consent comes to fruition, the importance of proper public education “in such a shift due to historic mistrust in the healthcare system and health inequities in communities of color.” Other responses similarly mention that it would be fine “as long as there is more information about the presumed consent program shared with the people” (figure 11). For the knowledge-based question, once more, there was a difference in familiarity with this term between affected and unaffected groups (figure 12 A & B).

**Figure 10.** Survey responses to “please indicate how open you would be to seeing presumed consent be implemented” ranging from 1 (not at all open) to 5 (very open)

**Figure 11.** Qualitative opinions of respondents on seeing presumed consent be implemented
The next topic the researcher asked respondents about was priority allocation, which was defined on the survey as a system in which registered donors receive a preference in the allocation of organs for transplant ahead of those who have not registered, excluding urgent life-saving transplants. The survey asked for the respondent's openness to the proposal, and the consensus is that there weren’t many strong feelings. While there were many fives and fours, most of the responses were unsure threes (figure 13). Because of this, priority allocation likely would not be the best option. The knowledge-based question for this topic again showed a knowledge gap between “affected” and “unaffected” groups (figure 14 A & B).

Figure 12. A. Affected group survey responses to “were you familiar with presumed consent prior to taking this survey?” B. Unaffected group survey responses to “were you familiar with presumed consent prior to taking this survey?”

Figure 13. Survey responses to “please indicate how open you would be to seeing a priority allocation system implemented” ranging from 1 (not at all open) to 5 (very open)
Lastly, the final topic respondents were asked about was the idea of financial incentives for donation, such as tax breaks, discounted driver’s license fees, and reimbursement for medical expenses. This was likely the most controversial of all the options. The most common answers were ones, so respondents were “not at all open” to implementing it for the most part, making it a definite “no” when it comes to short-term organ shortage solutions (figure 15). In the background knowledge question on this topic, again there is another example of the knowledge discrepancy between “affected” and “unaffected” individuals on matters related to the organ shortage crisis (figure 16 A & B).

Figure 14. A. Affected group survey responses to “had you heard of priority allocation prior to taking this survey?” B. Unaffected group survey responses to “had you heard of priority allocation prior to taking this survey?”

Figure 15. Survey responses to “please indicate how open you would be to seeing financial incentives for organ donation implemented” ranging from 1 (not at all open) to 5 (very open)
Figure 16. A. Affected group survey responses to “had you heard of financial incentives being considered for organ donation prior to taking this survey?” B. Unaffected group survey responses to “had you heard of financial incentives being considered for organ donation prior to taking this survey?”

Overall Findings

Overall, the findings of this research are that presumed consent had the highest approval rating of all proposals and would likely see the most support if put into place. This study also found that financial incentives had the lowest approval rating by far and would likely have the least support if put into place. From this research it has also been determined that there is indeed a need for further donation education for the general public, as can be seen in the 11% of respondents that would have registered if only they knew how or in each topic’s background knowledge questions. There is also general support for introducing K-12 donation curriculum, and so that is a possibility for the future as well.

Discussion

Implications

An implication for this research is that it formally provides the specific short-term approach to the organ shortage crisis with the highest public approval rating. This study could be used by those advocating for this issue to help push for a policy change to presumed consent. Another implication is that it displays a need for increased organ donation education, which could similarly be used to change education initiatives for the general public and potentially K-12, too.

Limitations

There were limitations to this research, with one large one being the COVID-19 pandemic affecting the distribution of the survey questionnaire. Prior to the pandemic, the researcher could have physically handed out surveys around the state, however that was not a possibility this school year. Due to this, the number of valid responses was limited to only 100 mostly alike individuals, which may have skewed the results more than if the sample size had been larger and more diverse. Another limitation the researcher had with the survey was that there were a few knowledge-based questions that depended on the honesty of the respondent. Despite the survey being anonymous, there is always a chance people might not have been truthful with their answers. This may have affected the results related to the need for further organ donation education. Lastly, a third limitation is that the research was only done in Massachusetts, and so there is a large chance that the state’s results may differ from that of others, especially considering Massachusetts is one of the healthcare capitals of the U.S. and may be overall more open to organ donation than other states. Therefore, to know for sure the best direction for the whole country, similar research to this could be done state by state, then compiled together to reach an understanding for the entire country.

Future Directions

There are many possible future directions for this research that would be exciting to see. The first being that, since this research was conducted only in Massachusetts, this same research could be performed in other states. This would also make it so that the conclusions could apply more accurately to the entire country, rather than just using responses from one state.
Next, a future researcher could ask for a respondent’s social class in their survey, which is something the researcher wishes they had done differently. While the researcher had anticipated that financial incentives for organ donation would be unpopular, as it was confirmed in this study, the results do raise the question if the very people who did like it were of a lower social class, and if those who opposed it might have been wealthier. While it wouldn’t change the researcher’s conclusions entirely, it would have been interesting to take note of.

Finally, this research could be picked up by somebody with more outreach resources so that the respondents would be more diverse, specifically when it comes to race and age. The respondent’s demographics can be seen in figures 17 and 18, which shows that those taking the survey were overwhelmingly middle-aged and white. It would have been interesting to be able to hear from younger and older generations as well as more people of color to see if those factors correlate with any specific trends in opinion.

**Figure 17.** Survey responses denoting respondent age

**Figure 18.** Survey responses denoting respondent ethnicity/ethnicities

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**References**


