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# Organ Donation: Gauging Perception, Interest, and Clarifying Misconceptions

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The University  
of Vermont

COLLEGE OF MEDICINE

# Organ Donation: Gauging Perception, Interest, and Clarifying Misconceptions

Tridu Huynh

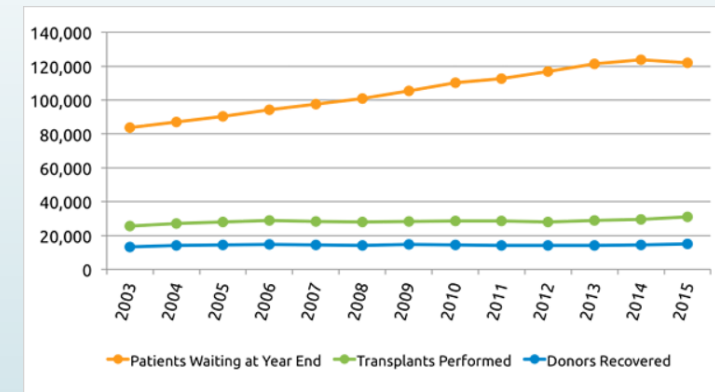
Swanton, VT

Dec 2016 - Jan 2017

Dr. Michael Corrigan, Swanton Family Medicine

# Organ Donation Statistics

- Around 120,000 people currently need a lifesaving organ transplant in the United States. In Vermont, that number is 64.
- On average, 22 people die each day while waiting for a transplant, nationally.
- Despite an increase in organ donation registration in recent years, the gap between supply and demand continues to widen (see graph below).<sup>1</sup>
- Only 52% of the national population are registered organ donors. In Vermont, that number is 44%.<sup>2</sup>
- Less than 1% of hospitals patients die in the specific set of circumstances that allows organ donation to be possible.
- State Representative Barbara Rachelson attempted to pass a bill that would make donor registration an opt-out option rather than the current opt-in system. The bill was ultimately not successful (see community perspective).
- Until we move to an opt-out system, maximizing organ donor registration is the only way to maximize the probabilities whereby such unique circumstances required by organ transplantation might be realized.



# Public Health Cost

- ▶ A combination of improvements in technology, post-transplant outcomes and a concurrent increase in the incidence of end-stage failure of vital organs have led to a dramatic rise in patients eligible for transplants within the last decade.
- ▶ The number of organ available, on the other hand, has not kept pace, leading to an increase in the number of patients waiting for a potential transplant.
- ▶ In 2011, over \$34 billion dollars were spent on dialysis patients with end-stage renal disease alone (the biggest organ waiting group).<sup>4</sup>
- ▶ A cost-benefit analysis by Dr. Held et al. estimated that taxpayers would save \$12 billion each year if living and deceased kidney donors were compensated \$45,000 and \$10,000, respectively. While no such cost-benefit analysis exist for a hypothetical transition to an opt-out system, it is needless to say that even more money would be saved.
- ▶ Dialysis is four times more expensive per quality-adjusted life-year compared to a transplant.
- ▶ About 5,000-10,000 dialysis patients die each year. 100,000 more have to suffer the process of dialysis for an average of 5 years before potentially receiving a transplant.<sup>3</sup>

# Community Perspective



- ▶ **Barbara Rachelson, Vermont State Representative**, introduced a bill in 2015 with the aim of changing organ donor registration from the current opt-in to an opt-out system in Vermont.
- ▶ Her initiative was “met with great misunderstanding and controversy,” which seemed to stem from a perception of the government intruding into one’s private life. She also mentioned that “while this has been an effective policy in other countries, it seems like Vermont isn’t ready for this step, yet.”
- ▶ She is currently working with the Vermont Organ Donor Program at UVM and the Vermont Department of Health in order to identify and address the misunderstandings in the hope of re-introducing the bill in the future.
- ▶ Fundamentally, she agrees that there needs to be an increased understanding and awareness of organ donation in the general public.
- ▶ Registering to be an organ donor can seem like a big commitment for some people, who might need time to think about it. She believes that periodic reminders, perhaps during yearly physicals, would be beneficial.



# Community Perspective

- ▶ **Bob Opel, UVM Medical Center Organ Procurement Coordinator**, believes that the main barriers to organ donation do not stem from people's unwillingness, but rather from misconceptions. Several themes he identified were:
  - ▶ A belief that one's organs were not fit for donation due to medical condition, substance use, or age,
  - ▶ Family members might be concerned that the donation process prolongs death or results in additional pain for the donor. They also might fear disfigurement of their loved ones or any compromise in their medical care.
  - ▶ Other common reasons include family's personal attachment to the donor's organs as well as philosophical/religious beliefs.
- ▶ Bob echoed State Representative Rachelson regarding the need for increased understanding and awareness of organ donation in the general populations, which this project aims to do.
- ▶ He also agrees that a doctor's office is a better setting for organ registration and talk compared to the DMV.
- ▶ Incorporating the topic of organ donation into advance directive talks at the doctor's office would be ideal, if there is time.

# Intervention and Methodology

- I designed and distributed a brochure with key information regarding organ donation to patients coming in to Dr. Corrigan's family practice in Swanton.
- Patients currently registered as organ donors were excluded from the study.
- Non-organ donors were asked to first read the informational flyer and then fill out the brief survey on the backside.
- The first two questions gauged the patient's willingness regarding becoming an organ donor before and after reading the informational flyer. Responses were recorded on a 1-5 Likert scale (very unlikely, unlikely, neutral, likely, very likely).
- The last question gauged the patient's willingness to register as an organ donor during an advanced directive talk with their provider. This was also recorded on a 1-5 Likert scale.
- Lastly, patients were asked to write down any concerns that might be keeping them from becoming an organ donor.
- A total of 50 surveys were filled out.
- Paired, parametric, two-tailed t-test and two-way ANOVA analysis was performed using GraphPad PRISM. Statistical significance was set at  $p < 0.05\%$ .

## WOULD YOU SAVE A LIFE IF YOU COULD?

- More than **5,000** people in New England and **123,000** in the USA are waiting for a life-saving transplant
- 22** people die every day due to not receiving the organ they need
- By becoming an organ donor, **one person** can save up to **eight lives** and enhance **fifty** others through tissue donation
- Donations are distributed based on recipient need, not wealth or status



## FREQUENTLY ASKED QUESTIONS

- Will the quality of my medical care be compromised?**
  - No, medical care teams are separate from transplant teams, so every effort will be made to save your life. Only after every effort to save your life has been exhausted and death has been confirmed would you become a candidate for organ donation.
- Will there be any cost to me?**
  - Not at all.
- Will I be able to donate only certain body parts?**
  - Yes, the choice is always yours, including removing your registration at any point in time.
- Will this affect my funeral?**
  - No, surgeons will ensure that you will be presentable for open casket service.
- I heard hospitals sell organs for profit, is that true?**
  - That is completely FALSE. Hospitals are forbidden from selling organs for profit, and organs can only be used as transplants.



## HOW TO GIVE LIFE

- Visit [www.organdonor.gov](http://www.organdonor.gov) or [www.donatelifevt.org](http://www.donatelifevt.org)
- It takes less than a few minutes to register in Vermont.

Age:

Gender:

	Very Unlikely	Unlikely	Neutral	Likely	Very Likely
<b>Before</b> reading this flyer, I was considering becoming an organ donor					
<b>After</b> reading this flyer, I am considering becoming an organ donor					
If given the opportunity to register as an organ donor during an advanced directive discussion with my doctor, I would do it					

Concerns/Reasons that keep me from becoming an organ donor :

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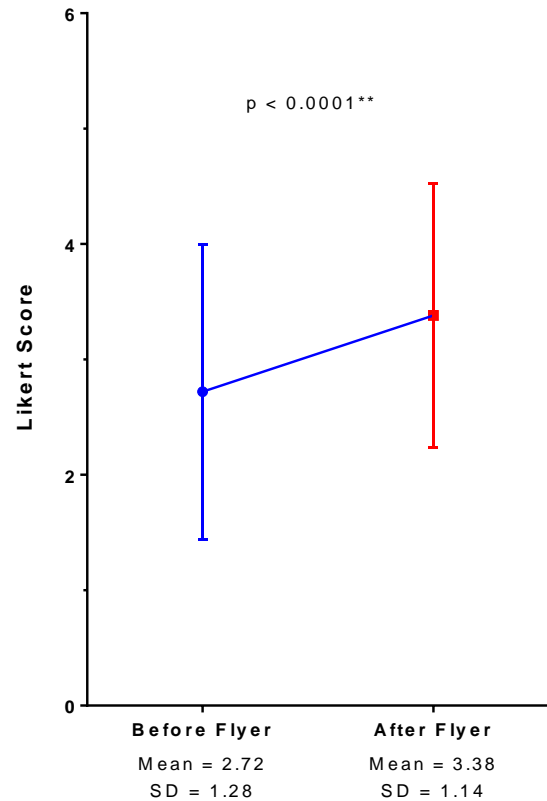
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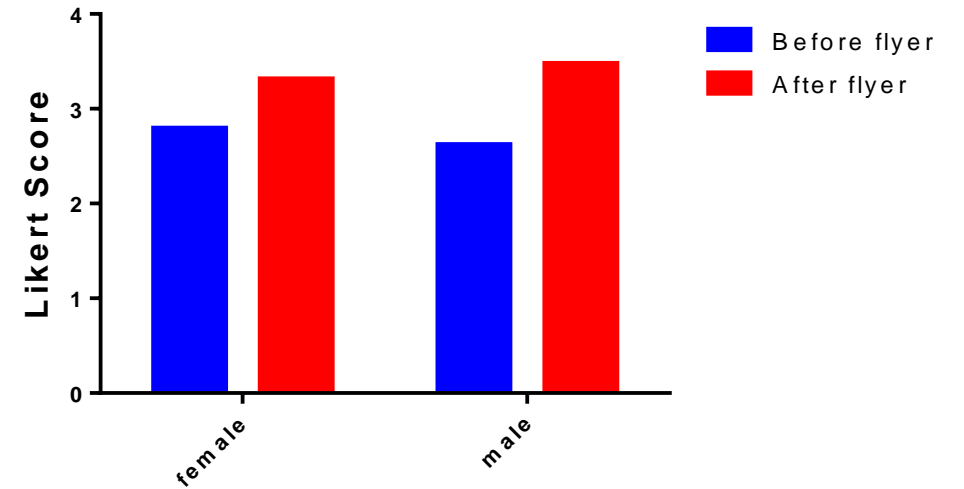
# Results

- 50 flyers filled out
- Age range: 21-90
- Mean age: 50
- 29 females, 21 males

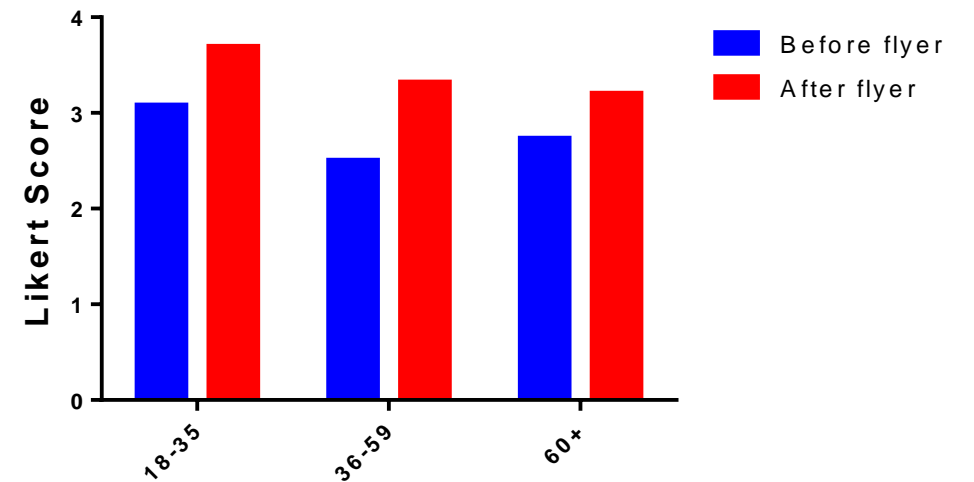
Likelihood of becoming an Organ Donor



Likelihood by Gender



Likelihood by Age



# Results

- Likelihood of registering if asked during advance directive talk mean: **3.31**
- **16/50** people filled out a concern/reason keeping them from registering:
  - **6/16** expressed concern that their organ would not be suitable for transplant due to either age, medical condition, or substance use
  - **4/16** expressed a religious or philosophical belief keeping them from registering
  - **4/16** expressed that they had no concern, but would need more time to think about it.
  - **2/16** expressed miscellaneous concerns

# Evaluation of effectiveness and limitations

- This brief intervention in a form of a flyer proved to be extremely efficient at encouraging patients to consider registering as organ donors overall ( $P < 0.0001$ ).
- There was no difference in effectiveness between genders or 3 arbitrarily defined age groups.
- This cohort of patients only showed a slight interest in registering as organ donors during an advance directive talk (mean = 3.31, neutral-likely).
- The most common reason cited for not becoming an organ donor was a belief that one's organs were not suitable for transplant due to either age, medical condition, or substance use.
- The 2 other most commonly cited reasons were philosophical or religious beliefs and a need of more time to think about registering.
- Limitations include:
  - Small sample size restricted to one geographical area of Vermont.
  - The lack of actual outcome (people actually registering online).
  - Asking both the before and after question at the same time (due to logistical constraints).



# Future directions

- ▶ Distribution of the survey to several primary care practices throughout Vermont in order to have a more representative picture of the state's perception and concerns regarding organ donation.
- ▶ Surveying providers in order to gauge interest in talking about organ donation during advance directives talks.
- ▶ Refinement of the brochure to address the most common concerns based on future final data (e.g. organ quality concern).
- ▶ Distribution of digital copy of brochure to receptive provider's offices for reference.
- ▶ Follow re-introduction of opt-out bill and support Ms. Rachelson in any way possible.
- ▶ If organ quality concern continues to be a predominant concern captured in future surveys, perhaps inform various organ donor programs such as OPTN or donatelifevt to address this concern on their website, as it currently is not.



# Acknowledgements



- ▶ I would like to thank Dr. Corrigan for giving me the idea for this project.
- ▶ I would also like to thank Dr. Corrigan's office, specifically Sarah and Kristen, for helping me distribute the flyers.
- ▶ I would like to thank State Representative Barbara Rachelson and Bob Opel for taking the time to meet with me.



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