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Brittany L. Rocque MSc
UVM

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IDENTIFICATION OF BARRIERS TO ORGAN DONATION: A PRIMARY CARE INTERVENTIONAL APPROACH

STOWE FAMILY PRACTICE
BRITTANY L. ROCQUE, MSC, MS3
FEBRUARY-MARCH 2017
PROJECT MENTOR: KATIE MARVIN, MD
PROBLEM IDENTIFICATION AND DESCRIPTION OF NEED

- Deceased donor organ and tissue donation is critical as it provides prolonged survival and improved quality of life for extremely sick/injured patients who eventually become recipients.

- Unfortunately, the national waiting list for organ donation includes 129,298 registrations with 5,484 registrations in New England. In Vermont, 61 patients are currently awaiting a life-saving transplant.\(^1\)

- Furthermore, waiting times are organ-dependent where median waiting time can be as lengthy as 1630 days (for a type O liver) and mortality while waiting for an organ is a significant issue.

- 52% of the United States population are registered organ donors yet only 44% of Vermonters are registered which is below the Donate Life America goal of >50% registration.\(^2\)

- It has been shown that an opt-out system for organ donation may be a solution\(^3\), however there are ethical and legal considerations that make the possibility of opt-out challenging. Increasing public awareness remains the current best solution for augmenting organ donation rates.

- The major interface of organ donation registration with the population is the Department of Motor Vehicles (DMV). The idea being that the majority of the population seeks a drivers license or form of identification from the DMV and therefore it is a good way to obtain registrations for organ donation. Unfortunately, the setting of the DMV may not be the optimal environment for education and dispelling misconceptions that deter individuals from registering to become an organ donor.
The Vermont Advance Directive short form is another means by which an individual could become registered as an organ donor. The pertinent section of the form is shown here:

There has been a recent movement among various primary care offices within the UVM health network to increase rates of patients who complete Advance Directives. In addition, the primary care office is an appropriate setting for a patient to discuss any questions pertinent to the Advance Directive – including those regarding organ/tissue donation.

Discussion of organ donation in the Family Medicine or Primary Care office is not a novel concept and may be an appropriate means by which to address the <50% organ donation registration rate in Vermont.
Patients with end-stage organ disease that become eligible for transplant account for sizable healthcare cost. Healthcare costs associated with End Stage Renal Disease (ESRD) and dialysis are significant and are trending upward. Renal transplants are, by far, the most common type of solid organ transplant and therefore account for the most significant cost considerations.

Per person per year (PPPY) expenditures are substantially less in patients with ESRD who underwent transplant compared with patients who undergo regular hemodialysis or peritoneal dialysis. Specifically, PPPY expenditures from Hemodialysis is just under $90,000 compared with around $35,000 in transplant patients. Peritoneal dialysis PPPY cost is over $70,000. Furthermore, total ESRD-Related Medicare expenditures are around 28 billion dollars with approximately 25 billion being attributable to hemodialysis.6

This suggests that increases in renal transplant relative to dialysis in patients with ESRD may confer a substantial cost benefit to Medicare expenditures and the overall healthcare system.

There would potentially be additional benefit of cost-savings and convenience to patients in rural communities like Stowe, VT that do not have easy access to a dialysis center.
COMMUNITY PERSPECTIVE

- Representative of New England Donor Services:
  - Addressing organ donation in doctors offices is not a new concept and there are a number of state grants that have supported this in the past. There have been mixed results with trying to educate the public in doctors offices due to time constraints. About 70% of the population goes to the DMV and therefore that has been the primary source of registration for organ donation. Public awareness campaigns are largely successful in increasing organ donation rates. If primary care offices would continue the efforts of adding to the conversation with their patients, it would be a great help for increasing organ donation rates.

- Lamoille County Practicing Family Medicine Physician
  - Barriers to organ donation can be addressed in the Primary Care office, particularly during annual well exams. Issues with this would include time constraints (i.e., it would be difficult to ask the nurses to do one more thing with the patients). In addition, sometimes annual physicals cover a lot of problems however organ donation may be an important and interesting topic to cover.

- Patient and registered organ donor from Lamoille County Vermont Community:
  - Believes that organ donation is “simply the right thing to do”, however thought that some individuals avoid being organ donors because they are concerned that if they signed up to be an organ donor, that somehow their healthcare needs would not be prioritized and/or doctors would give up on treating them prior to giving them an optimal treatment strategy. The patient also acknowledged that many other fears or concerns may pose a potential barrier to organ donation.

*Note that perspectives are paraphrased unless in quotations – names withheld.*
INTERVENTION DESIGN

- Intervention:
  - Supply information in the form of an information sheet/brochure in order to dispel common misconceptions and myths regarding deceased organ and tissue donation.

- Methodology:
  - Supply patients' coming to Family Medicine practice for annual well exams with the informational sheet which includes information regarding organ donation statistics and frequently asked questions. Annual well exams were presumed to be the optimal time to address issues regarding Advance Directive and organ donation status in the Primary Care setting. The brochure was designed to anticipate common misconceptions or concerns regarding organ and tissue donation.
  - Survey patients' attitudes before and after reading the brochure to assess intervention efficacy Using a 1-5 Likert Scale (very unlikely, unlikely, neutral, likely, very likely).
  - Survey Patients for any remaining questions or concerns regarding organ donation.
  - Patients under 18 years old and registered organ donors were excluded.
  - A total of 6 Patients undergoing annual well exam met study criteria and agreed to fill out the survey.
INTRODUCTION AND METHODOLOGY INFORMATIONAL HANDOUT AND SURVEY

Front:

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?
  - No, 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

- It takes less than a few minutes to register in Vermont.

Back:

Age: ____________________________

Gender: ____________________________

Before reading this flyer, I was considering becoming an organ donor - ________

Very Unlikely  Unlikely  Neutral  Likely  Very Likely

After 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:

________________________________________________________________________

________________________________________________________________________
RESULTS AND INTERPRETATION

Likelihood of donation

<table>
<thead>
<tr>
<th></th>
<th>Before</th>
<th>After</th>
<th>Advanced</th>
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<tbody>
<tr>
<td>6 patient average</td>
<td>2.5</td>
<td>2.5</td>
<td>2.7</td>
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Results Based on the 1-5 Likert Scale:
(1 - Very Unlikely, 2 - Unlikely, 3 - Neutral, 4 - Likely, 5 - Very Likely)

Qualitative Feedback:
3 assumed their organs would not be usable
2 wanted more time to think
0 changed likelihood after reading brochure material

Interpretation
- Low volume of survey participation
- Misconceptions impacted 50% of patients and these patients were more unlikely to donate.
- Time to consider impacted 30% of patients and these patients were more neutral to donation.
- It appears that:
  - If participants needed consideration they would, by default not donate
  - If they had considered and, they did so with misconceptions
  - The combination had a 5/6 cause of unlikely to donate
EVALUATION OF EFFECTIVENESS AND LIMITATIONS

- According to the sample of patients obtained from this intervention, the informational sheet alone was not effective in changing the perspectives of patients who were not registered as organ donors.

- Analysis of the reasons or concerns regarding avoiding organ donation revealed that ‘lack of time for consideration’ was one barrier to signing up to be an organ donor. It is possible that repeated exposure and clarification may be needed for some patients to decided to become organ donors.

- Another common reason cited for not opting into organ donation was that the patient felt that they were too old or that their organs would not be viable for transplant. Again, this misconception should ideally be addressed with future intervention such as a brief dialogue - which was not performed for in the context of this study.

- From discussing the topic with many patients it became clear that this was not an easy topic for some individuals as it required an assessment of wishes after death and some patients may wish to avoid confrontation with the subject altogether.

- Additionally, some personal spiritual or philosophical beliefs may be prohibitive although it is notable that none of our participants admitted to any such restrictions.

- This study was limited by sample size. The exclusion criterion of only patients present for annual well exams may have been too restrictive for the desired analysis.
Future extension of this project should include adapting the Frequently Asked Questions to address concerns regarding the donors perception that their organs are not viable, time to think and changing one's mind.

There have been several studies with mixed results on whether or not organ donation discussion in the primary care setting could become an effective means of increasing the number of registered donors. Future study should explore the optimal context in which this intervention is effective. Many questions could be explored such as:

- Is a simple conversation more effective than an informational brochure?
- Are some types of misconceptions easier to resolve than others?
- Are repeated conversations necessary for patients to be given the time they need to contemplate their choice regarding organ donation?
- Are rural communities or non-rural communities more likely to respond to such an intervention?

Extending beyond the issue of individual opt-in organ donor status is the public opinion, potential benefits and potential issues that surround opt-out organ donation. Several efforts have been made to explore opt-out organ donation, however there is currently very little support for that notion in the United States. It would be interesting to explore the attitudes of non organ donor patients to the notion of an opt-out system.


