Family Physicians’ Role in Recruitment of Organ Donors

Susan A. Bidigare, MD, MS; Aaron R. Ellis, MD

Objective: To determine if family physicians can increase the commitment of patients to organ donation.

Design: Prospective, systematically randomized, cross-sectional study.

Setting: Family practice residency medical center associated with an urban, community-based teaching institution.

Patients: A total of 300 patients aged 18 years or older, able to give consent, and being seen for non–life-threatening visits; 247 patients returned valid second questionnaires.

Interventions: Instruments included 2 self-administered questionnaires. All patients received questionnaire 1 to be completed in the examination room. They also received an informational brochure, a Michigan Secretary of State driver’s license sticker (donor sticker) and questionnaire 2. Group 1 received the written materials only. Group 2 received written materials plus a brief verbal discussion by the investigators following a standard protocol. Questionnaire 2 was to be completed and returned after the interventions.

Main Outcome Measures: Self-reported completion of donor sticker was used to evaluate commitment to organ donation. Knowledge scores were summed for pre-intervention and post-intervention means.

Results: Thirty-three percent of patients had already committed to organ donation prior to the study. Of those not previously committed, 40% decided to do so after the interventions. There was no statistical difference in the recruitment of donors between the 2 intervention groups. Of new donors identified, 65% stated their decision was due to written materials provided, while 34% attributed this to discussion with a physician. Thirty-five percent of the family members made arrangements to donate their own organs after the discussion with the patient. There was a significant difference between mean pretest and posttest knowledge scores (10 questions; 7.9 vs 9.2; \( P < .01 \)).

Conclusion: Family physicians can increase the commitment to organ donation through a relatively simple intervention.

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There is a critical shortage of organs for transplantation. Thousands of potential recipients await organs, while many die while waiting. There are also numerous cadaveric patients who could be donors but are not utilized. Lipcamen and Giles\(^1\) found that more than 23,000 people were involved in accidents that left them brain-dead in the course of a year. In only an estimated 3000 of those 23,000 cases were organs and tissues donated. Many reasons have been posed for the lack of donation. In a survey by Crosby and Waters,\(^2\) physicians and nurses reported that lack of information about the suitability of donors led to many potential donors being missed. Chatterjee et al\(^3\) found that only 25% of patients referred as kidney donors in a large university hospital became donors. Reasons cited for this low donor rate were inadequate awareness and education in identifying donors and notifying the appropriate services. Lack of communication and cooperation between the medical and nursing staff was found to result in referrals being made too late. On the other hand, Siminoff et al\(^4\) compared the

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From the Department of Family Practice, St John Hospital and Medical Center, Detroit, Mich. Dr Bidigare is now with the Department of Family Medicine, Wayne State University, Detroit.
PATIENTS AND METHODS

A prospective cross-sectional study was conducted to determine if discussion and education by family physicians can increase patients' and families' commitment to organ donation. A nonprobability sample of convenience was obtained from a population of patients and families seeking health care at the St John Family Medical Center. This sample included a total of 300 patients seen by 2 residents and 1 attending physician who met the following inclusion criteria: age 18 years or older, able to give consent, and being seen for non–life-threatening visits. Data collection instruments consisted of self-administered questionnaires developed by the investigators (S.A.B. and A.R.E.). The first questionnaire was designed to elicit patients' and families' knowledge and attitudes regarding organ donation. A second follow-up questionnaire was developed to elicit data regarding the patients' and families' decision to complete a driver's license organ and tissue donation sticker (donor sticker) provided by the Michigan Secretary of State. This questionnaire also served as a posttest, designed to determine if patients' knowledge about organ donation increased after an educational intervention. Data was collected at the Family Medical Center, via mail, and via telephone. Patients seen at the Family Medical Center were asked to complete an initial questionnaire at the time of their office visit. This included a determination of whether they had already signed a donor sticker. A pamphlet, which was developed by the investigator (S.A.B.), was given out. This pamphlet answered commonly asked questions regarding organ donation. An organ donor sticker was provided. Patients were systematically randomized to 1 of 2 intervention groups: those receiving informational material only and informational material along with a brief word of encouragement from their treating physician (Figure). Every fourth patient was assigned to the second group. All patients were given a second questionnaire with a self-addressed envelope with instructions to return it indicating whether they had made a decision regarding their commitment to organ donation, what was their decision, and whether they had discussed this with their family. Information was also sought in this questionnaire to determine how the patient came to this decision, and what effect the family physician had on this decision. Comparisons were made between the number of patients originally having donor stickers and the number after interventions occurred.

The second questionnaire also determined whether knowledge scores regarding organ donation could be increased through education by the family physician. Patients not returning questionnaires after 3 weeks were contacted by telephone to complete the questionnaire. Data were analyzed using descriptive and correlational statistics. SPSS for Windows statistical software (SPSS Inc, Chicago, Ill) was used.

attitudes and knowledge of health care professionals and their performance when faced with a donor-eligible patient. They found attitudes to be of more importance than knowledge in the successful retrieval of organs. A study by Pearson and Zurynski examined the attitudes and practices of intensivists with regard to brain death and organ donation. It was found that although intensivists are involved in the request for organ donation 90% of the time, one third do not believe it is their role to request organ donation. In addition, one third of the intensivists believed that it is solely their responsibility to decide if families should be approached for donation. Some reasons identified for not requesting donation include language or communication problems, perceptions of cultural differences, and degree of family distress. Studies also show that there is a lack of family physician involvement in organ procurement. In a study by Coolican and Swanson, it was found that 69% of the primary care physicians they surveyed never discussed organ donation with their patients during routine office visits and only 5% had donation information available. Another study by Spielman and Verhulst surveyed family physicians' advisory roles in organ retrieval. They found that 67% of physicians surveyed believe that an individual's desire to donate should supersede, even when a patient's family preferred not to donate. However, only a small minority encouraged their patients to complete a health care power of attorney, which the authors believe is the best mechanism to achieve patients' wishes. It is also thought that many patients and families would be willing to donate if the subject was discussed. Morris et al, in a study of pediatric patients who had no contraindications to organ donation, found that of the 19 eligible donors in a 31-month period, 18 donor families were approached for donation. All 18 families gave permission for donation.

A review of the literature shows that there is a lack of information regarding the family practice physician's involvement in organ donor recruitment. It is hypothesized that family physicians can have a major impact on patients' and families' insight and beliefs regarding organ procurement through discussion and education. The purpose of this study was to determine if by educating patients and their families and promoting discussion of these issues, family practice physicians can increase the commitment to organ donation.

RESULTS

DONOR RECRUITMENT

Three hundred valid questionnaires were obtained. Of these 300, 98 (33%) respondents indicated they had al-
ready made a commitment to organ donation via driver's license stickers. Two hundred forty-seven respondents completed questionnaire 2.

Of the 247 respondents from whom a second valid questionnaire was obtained, 71 had made the decision to donate previously, leaving a pool of 176 who were undecided prior to the interventions. After the interventions, 71 (40%) of the 176 reported making a commitment to organ donation. Forty-six (65%) of the 71 stated they did so because of the written materials provided by the investigators. Twenty-four (34%) identified the discussion that occurred between the physician and patient as the reason for their decision after the intervention. There was no significant difference between the group of patients who received only written materials and those receiving written materials and participating in the discussion with the physician.

Commitment rates were also analyzed based on the 2 different interventions. Group 1 included patients who received only written materials. Any discussion that occurred in this group was at the patients’ initiation. Group 2 received the standardized verbal protocol along with the written materials. Forty patients received the scripted verbal protocol. Of those 40, 12 (30%) made the decision to donate after the intervention. There were 125 encounters in which the patient received only written materials and there was no initiation of discussion by the physician. Of these encounters, 53 (42%) made the decision to donate. In 21 of these encounters the patient and/or family initiated a discussion about donation during the office visit. In this group, 11 (52%) of the patients made the decision to donate. In the group of 104 encounters in which only written materials were provided and no discussion occurred, 42 (40%) made the decision to donate.

Regarding the patient’s discussion of their decision toward donation with their family, 85% stated they had spoken with their family regarding their decision. The majority of respondents (55%) reported that their family had accepted their decision without question. Thirty-five percent said that their family had also taken steps to discuss this with all patients—the public needs education, eg, “Life from death, how appropriate!”; and (4) identification of the need for more education, eg, “Doctors need to discuss this with all patients—the public needs education on these issues.” A minority of respondents (n = 6) cited negative aspects regarding donation. Some of these comments included (1) concerns that organs are not distributed equitably, eg, “People with money and power get organs first”; (2) mistrust as to whether physicians would make all efforts to save accident victims’ lives if they knew they were organ donors, eg, “As long as the doctor would not help me on my way to get donor parts”; and (3) concerns regarding body mutilation, eg, “I don’t want to be opened and have my parts dug out except if it’s for a relative or close friend.”

Prior to the interventions, patients were asked to indicate their feelings regarding organ donation using a Likert-type scale. Using a scale from 1 (strongly disagree) to 6 (strongly agree), 87% of respondents approved of organ donation to varying degrees. When asked to comment on organ donation, a large proportion of patients (n = 43) added positive comments, some of them included (1) statements that it is the right thing to do to help fellow humans; (2) remarks that it is a sin not to donate or that it is “God’s plan for us to help each other” or “That’s what God gave them to me for”; (3) comments that saving lives through death was important, eg, “As long as the doctor would not help me on my way to get donor parts”; and (3) concerns regarding body mutilation, eg, “I don’t want to be opened and have my parts dug out except if it’s for a relative or close friend.”

ATTITUDES

On the initial questionnaire, 33% of the patients sampled had already indicated their desire to donate organs via their driver's license, while 32% reported that although they had not done so, they would have no objection to their family donating their organs after their death. Fourteen percent stated that they had not already indicated their wishes to donate but would do so if given the appropriate materials. Five percent reported that under no circumstances would they want their organs donated. Seventeen percent stated they were uncertain.

KNOWLEDGE

Scores for the knowledge variables were summed for both the pretest and posttest; the total number of questions was 10. The mean scores on the pretest and posttest for the entire group were 7.9 and 9.2, showing a significant increase after the intervention (P < .01).
The purpose of this study was to identify the attitudes, beliefs, and knowledge of patients regarding organ donation and to determine if by educating patients and their families and promoting discussion of these issues, family practice physicians can increase the commitment to organ donation. There was a significant change in the commitment of patients after the interventions. Forty percent of the patients in this study who had not previously signed a driver’s license organ donor sticker did so after these interventions. Sixty-five percent of these new donors stated they did this after receiving and reviewing the written materials provided them during routine office visits. Thirty-four percent reported they did so because of the discussion that occurred between the physician and patient. In addition, 35% of respondents stated that, after discussing their wishes with their family, some of their family members took steps to donate their own organs; thus, the interventions had a coattailing effect on increasing the commitment to donation.

It was hypothesized that a brief physician-initiated discussion might positively affect recruitment of organ donors compared with the distribution of materials alone. However, this assumption was not supported by the outcome data (commitment rate for physician-initiated discussion group was 30% vs 42% for no physician-initiated discussion). In an effort not to disrupt patient flow in the office, the protocol script was kept at a minimum. It is possible that it was too brief to be effective. It also must be noted that many patients independently initiated a discussion with their physician and attributed their decision to become an organ donor to this interaction.

The purpose of one of the research questions was to determine if a brief, verbal intervention might affect the commitment to organ donation. A flaw in this was that although patients were assigned to either receive the written materials and the verbal protocol or only the written materials, many in the second group initiated the discussion of donation themselves, thereby affecting the results. The ability to generalize the results of the interventions based on the premise that the discussion be initiated by the physician is limited.

Regarding pretest scores assessing the knowledge of organ donation, areas such as consent issues, payment aspects of transplantation, declaration of brain death, and state laws all showed significant knowledge deficits. Providing patients with written educational materials during an office-based encounter appeared to impact these knowledge scores. Distribution of these materials to a larger patient population is suggested to increase this knowledge on a wider scale. It is uncertain whether a mass mailing of this material would have the same impact as an office-based intervention. This could also be generalized to other patient care areas and topics for which knowledge deficits have been identified.

The data suggest that the family physician-patient encounter is an excellent opportunity for educating patients and increasing the commitment to organ donation. The intervention was brief enough not to be disruptive to office schedules. Although it was found that discussion of these issues was no more beneficial than was the use of written materials alone, family physicians must be knowledgeable regarding organ donation to respond to the questions and concerns of their patients. The study demonstrated that a relatively simple intervention consisting of a brochure positively affected the commitment of patients and their families to organ donation in one sample of patients presenting to a family practice medical center.

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Reprints: Susan Bidigare, MD, MS, Wayne State University, Department of Family Medicine, 4J-UHC, 4201 St Antoine, Detroit, MI 48201 (e-mail: sbidigar@med.wayne.edu).

REFERENCES

My interest in organ donation began while working as a nurse in the intensive care unit prior to entering medical school. I found it extremely frustrating that so many people died without their family being offered the option of organ donation. To change this, I created a team of nurses called the TransLife Team, whose goal was to increase the awareness of the need for organ donation within the hospital, and to work one-on-one with the potential donor patient's family, the neurosurgeons, and the organ procurement team. The number of donors increased with this approach, and the actual process of donation became much easier. Of even more importance to me, the satisfaction that the donor families felt was even more apparent. After nearly every organ recovery, I would receive letters and phone calls from donor families thanking the team for our efforts. One father of a 17-year-old called the morning after his son's funeral. He related that the family just wanted to thank us, because were it not for their being able to achieve some good out of this situation, they didn't know how they would have coped with their son's death. Comments like this made all of our long hours worthwhile.

My efforts in promoting organ donation waned somewhat during medical school, mostly from lack of time. When it became time to do our resident research project I instantly thought of organ donation. Wouldn't it make sense to talk about organ donation with our patients long before their death, before emotions and despair intervene? A literature search showed that there was a lack of information about the role of family physicians in the promotion of organ donation during routine primary care visits. Maybe there was a project in this. Finding a faculty advisor was the next step. As Residency Program Director, Dr Aaron Ellis already had more than enough responsibilities. He readily agreed, however, to be the project advisor and furthermore volunteered to participate in the data collection, thereby increasing the number of patients and adding the further dimension of including a well-established faculty practice. Hence the project was born. We have shown that a very simple, time-effective intervention can increase our patients' commitment to organ donation when the intervention is conducted during routine office visits. Our goal is that more family physicians will begin discussing organ donation with their patients so that someday there will be enough organs to go around.

Susan A. Bidigare, MD
St Clair Shores, Mich