A multidisciplinary program to educate and advocate for living donors

Education is critical in decision making and the informed consent process in prospective living donors. Little has been written about how and what living donors should be taught. This article describes a multidisciplinary program for living donor education at the University of Virginia. The goals of the program are to impart information needed for prospective donors to make an informed decision and to independently evaluate donors’ medical and psychosocial suitability. A partnership between the transplant department and an independent donor advocacy team establishes an environment conducive to education. By embracing independence, transparency, partnership, and advocacy, our program permits bidirectional education. This partnership facilitates unbiased understanding and appreciation of this education and considers each individual’s unique circumstances when making informed decisions. Likewise, prospective donors educate the team about their circumstances, which helps the team safeguard the prospective donor and may enhance the safety of prospective donors and the perceived integrity of living organ donation. (Progress in Transplantation. 2008;18:284-289)

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Education of patients, particularly by a multidisciplinary team, is imperative to ensure that those who choose to be living donors are making well-informed decisions. At the University of Virginia, the exchange of information and education is bidirectional. Prospective donors are given information that they need to make an informed decision, whereas the evaluation team gains knowledge about the prospective donor. The evaluation team can simultaneously tailor both the educational methods and content on the basis of a particular individual’s needs. Rapport and respect may foster an environment where education can occur, creating the opportunity for prospective donors to make informed decisions.

Through the bidirectional educational process, the ultimate goal is informed consent by the prospective donor. Informed consent in living organ donation has been described as “a process, not an event,” and its importance has been elegantly deliberated and reviewed by the Ethics Committee of the Transplantation Society as part of the Amsterdam Forum. The committee proposes that decisions about living donation take place in an environment in which the donor is able to decide autonomously. This proposal underscores the importance of minimizing risk to the prospective donor, as well as minimizing risk to the public’s perception of living organ donation. The Ethics Committee recommends that donor evaluations include medical and psychological assessments by health care providers who are not involved with recipient care, thus providing prospective donors with an advocate who is independent of the recipient.

Drawing on social cognition theory, the educational process involves pairing prospective donors with “mentors” from various backgrounds to elicit and expand the donors’ understanding. Mentors include a dedicated nurse coordinator, a family medicine physician, a social worker, a psychologist, and a transplant surgeon. Mentors may also include former donors willing to talk to prospective donors about their experience. Mentors may use principles of social cognition to aid growth.
A primary principle is the assessment of each prospective donor’s “zone of proximal development.” Assessing the zone of proximal development refers to identifying the discrepancy between what prospective donors know independently as they begin the evaluation versus what they can potentially understand with the assistance of mentors. This assessment determines current knowledge, needed knowledge, and how to provide the necessary “scaffold” for prospective donors to bridge the gap between what they know and what they need to know to make an informed decision.3

Educational Process

The process of educating prospective living donors is continual and multidisciplinary in nature at the University of Virginia. Along the way, the various members of the donor evaluation and transplant teams establish what their individual roles are with regard to the prospective donor. The evaluation sequence is presented in the Figure. Prospective donors hear oftentimes-repeated information about the donation process from each member of the education team, receiving a consistent message throughout the process. The ethics statement of the Vancouver Forum suggests that it is the responsibility of the transplant team to share information with prospective donors in a repetitive fashion.1

The initial interaction for all donors is with a dedicated living donor nurse coordinator. This nurse coordinator remains the primary point of contact throughout the donor evaluation, surgery, and postoperatively. The first interaction, whether on the phone, via e-mail, or face to face in the clinic setting, is when the nurse coordinator assesses the individual’s medical history. The nurse coordinator is the first to educate prospective donors about what type of individual can or cannot be a donor, what tests are done, and what general risks are involved with being a donor. Prospective donors are given a written educational handbook about the evaluation process and commonly asked questions (see Table). The prospective donors are also provided with...
Table: Contents of the living kidney donor and living liver donor handbooks

<table>
<thead>
<tr>
<th>Introduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>The transplant team</td>
</tr>
<tr>
<td>Renal failure and transplantation/liver failure and transplantation</td>
</tr>
<tr>
<td>Why living donation?</td>
</tr>
<tr>
<td>Who can be a living donor?</td>
</tr>
<tr>
<td>Donor evaluation process</td>
</tr>
<tr>
<td>Medical screening</td>
</tr>
<tr>
<td>Blood typing</td>
</tr>
<tr>
<td>Renal function testing (for potential renal donors)</td>
</tr>
<tr>
<td>Donor advocacy team</td>
</tr>
<tr>
<td>Medical evaluation</td>
</tr>
<tr>
<td>Lab testing</td>
</tr>
<tr>
<td>Radiology testing</td>
</tr>
<tr>
<td>Psychosocial evaluation</td>
</tr>
<tr>
<td>Psychologist</td>
</tr>
<tr>
<td>Social worker</td>
</tr>
<tr>
<td>Surgical evaluation</td>
</tr>
<tr>
<td>The surgical experience</td>
</tr>
<tr>
<td>Recovery and follow-up</td>
</tr>
<tr>
<td>Commonly asked questions</td>
</tr>
</tbody>
</table>

These educational handbooks can be viewed online at: www.healthsystem.virginia.edu/internet/transplant/patientinfo/DonorPatientInfo.cfm.

an illustrated guide to donation that shows how the living donor surgery is performed. Prospective donors are informed from the first point of contact that they may withdraw from the process at any time. If the individual is an appropriate medical candidate, has a compatible blood type, and is interested in proceeding with the evaluation, he or she is referred to the donor advocacy team (DAT).

**Donor Advocacy Team**

The DAT model at the University of Virginia includes a family medicine physician responsible for completing a detailed medical history and physical examination and facilitating orders of all tests deemed appropriate, with the goal of assessing overall medical well-being. A social worker evaluates social, occupational, and financial resource stability. Last, a psychologist evaluates the psychological history, current psychological functioning, reasoning process, and potential vulnerabilities that the donor may have regarding the donation process. All members of the DAT are familiar with global transplantation issues and are well versed in the living donation evaluation process and recovery.

**Four Core Values**

The DAT at the University of Virginia developed core values on the basis of input from our multidisciplinary team to create independent donor advocacy. Our philosophy focuses on these 4 values to enhance the educational process with prospective donors: independence, transparency, partnership, and advocacy.

We believe that following these tenets minimizes the bias that a recipient-based evaluation would truly pose to donors, as well as the appearance of a conflict of interest, an important responsibility laid out by the Amsterdam Forum. Adherence to these tenets also minimizes perceptions of paternalism, or taking away prospective donors’ autonomy in the decision. These objectives facilitate rapport and increase educational opportunities for donors to acquire and apply new knowledge. In addition, the process educates the DAT members in terms of understanding and appreciating each prospective donor’s circumstances.

**Independence.** As the family medicine physicians, social worker, and psychologists are not faculty in the transplant center, they maintain the tenet of independence. By highlighting this independence, the DAT providers invite open discussion and educational exchange between the prospective donor and the DAT without fear that exchange will lead to consequences (ie, getting back to the potential recipient, or those primarily caring for the recipient). The DAT members accurately inform prospective donors that they are not involved in the evaluation or disposition of the recipient, and remain “blind” to the recipient’s issues to minimize the bias that separately evaluating the recipient might pose. The DAT members do, however, ask about prospective donors’ understanding of the recipient’s condition, as this often educates DAT members about the motivation and reasoning in the prospective donor’s decision-making process.

An independent DAT prevents “working both sides of the street,” but it does allow for a “2-way street” in which both the living donor and the treatment team benefit from bidirectional education. Donors are provided with general education about the known risks inherent to the process, the possible benefits, and the need for support and nurturance during recovery. Additionally, both donors and DAT providers acquire an appreciation for the unique strengths and vulnerabilities that a prospective donor brings to the donor evaluation process. This facilitates a collaborative approach, recognizing the interplay of factors considered in the prospective donor’s autonomous decision to move forward or not.

**Transparency.** The DAT members verbalize the goal of transparency in the evaluation and educational process. This transparency applies not only to the DAT’s role, donor evaluation process, and donation itself, but also to the perceived strengths and perceived concerns the DAT member has regarding the prospective donor.
Prospective donors know that they will learn straight from the DAT member what the recommendations will be, and, if present, any reservations about candidacy as well as suggestions about how they might be resolved. Many prospective donors show visible relief upon learning that they will hear the impressions directly from the DAT member. Thus addressing preliminary worries that the donor would be discussed “behind closed doors” improves attention, openness of discussion, and education. In this way, we believe that transparency on the part of the DAT invites a greater probability for transparency by the donor, benefiting and exemplifying our bidirectional educational process.

Partnership. Establishing an explicit “physician-patient partnership” with the prospective donor also augments the educational process. By informing prospective donors that the primary role of the team is to ensure and provide for their care, a bond is established that parallels, yet extends what an instructor takes on with a student, or a mentor assumes for a mentee. By invoking this partnership, it is emphasized that this relationship is bidirectional. In this way, DAT members entreat the prospective donor to teach them about the issues and perspectives the donor considers important, and how this decision has affected, is affecting, and may affect the donor in the future.

Advocacy. To advocate, the DAT must create an environment conducive to education and must impart information in a way that the prospective donor can hear. Advocacy also depends on the team members’ ability to listen to the needs and wishes, as well as the concerns and fears, of the prospective donor. This input is necessary for the DAT to balance the relevant sum of “pros and cons” to render an opinion about donor candidacy and/or how to strengthen candidacy if the prospective donor elects to move forward. The process was designed so that the characteristics of independence, transparency, and partnership would allow DAT to serve as advocates for the interests of prospective donors.

Medical Evaluation
The medical examination by the independent family physician consists of a review of any records and test results, including renal function testing for potential kidney donors. The physician provides an explanation of the transplant and donation processes and a review of the necessary tests and the purpose of each, emphasizing the fact that donor safety is the primary reason for the process. The candidate is informed again that he or she may withdraw without bias at any time, and the medical examiner will assume responsibility to minimize potential intimidation from other sources should the candidate change his or her mind. In our perspective, this piece of our educational process is critical, because it puts the prospective donor in the “driver’s seat,” serves to establish and maintain rapport with the DAT, and creates a good medium for continued education throughout the decision-making process.

The medical history is reviewed in detail and a standard physical examination is performed, with the goal of determining medical suitability. Prospective donors are encouraged to have appropriate health maintenance examinations performed at appropriate intervals. Candidates are encouraged to ask questions at any time during the interview or examination, but can also follow up with questions generated throughout later stages of the DAT process.

Psychological Evaluation
At the University of Virginia, a licensed clinical psychologist completes the psychological evaluation component of the DAT. Although no standardized assessment tools are used, a uniform, structured interview is employed as a template for each prospective donor. This interview is supplemented by more thorough examination of areas of vulnerability identified during any particular case. The psychologist presents the DAT relationship to prospective donors as an alliance, or partnership, founded upon a clear doctor-patient bond. This partnership, absolutely dependent on rapport, furthers the prospective donor’s education about what to expect. Not only the medical issues associated with donation, but also the psychological, interpersonal, and quality-of-life aspects are openly discussed. In this way, it is demonstrated that the DAT is committed to considering a prospective donor as a whole person, not simply an organ donor; moreover, it is demonstrated that all aspects of health, not just medical aspects, are important for consideration.

Semistructured Interview: The structured interview includes open-ended questions with further queries to flesh out prospective donor responses. These questions are geared toward assessing competency, but also a thorough investigation of the medical, psychological, and psychosocial dynamics that might influence decisions. Competency is evaluated by eliciting donors’ understanding of what the donation process involves, the appreciation of how the process could affect them, the expression of a clear decision, and the ability to provide a rationale for that decision. The psychologist investigates for any evidence of overt or subtle coercion prompting the evaluation, as well as any suggestion that donation would be contingent upon financial remuneration. Although this process is somewhat subjective, efforts are made by the psychologists to keep the purpose clear—to serve the best interests of the prospective donors and support them regardless of their decision. Open-ended interview questions include the following:
• What are the circumstances of deciding to donate (ie, history of the decision)?
• What are the reactions of others (especially family) and the recipient?
• How would you describe family relationships in general?
• How do you feel about what you have learned about donation thus far?
• Do you have any confusion, qualms, or concerns about what you have been told?
• What can you recall about what happens during donation and during recovery?
• What risks do you remember?
• What possible benefits might there be?
• What is the best part about donating for you?
• What is your greatest worry?
• If the evaluation process found that you could not donate, what would you do to cope?

If you donated, and the recipient rejected your organ, what would you do to cope?

Donor Perceptions and Psychological Evaluation.
In an effort to examine the complex interplay of other factors, the role and impact of the prospective donor’s health history, including surgical history, and their understanding of the pain associated with recovery is explored. A thorough discussion of mental health and substance abuse history is also a critical piece of the assessment, including an assessment of safety (ie, risk of suicide). Although psychiatric history does not, in and of itself, contraindicate donation, it is important that the prospective donor with such a history can show stability of his or her symptoms and a reasonable plan for securing ongoing support and/or treatment. Often in these cases, outside treating professionals are asked to comment, with donor consent, about their perception of the donor’s stability, response to treatment, thoughts about the impact of donation, and any comments about factors that may be motivating the prospective donor.

A thorough discussion of the plan for recuperation is also an essential piece of the donor education process in terms of what needs donors anticipate from donating and who is able and willing to assist in meeting those needs. It is a further opportunity to invoke the partnership that the DAT undertakes with the individual to educate them about potential implications of donating. Consistent with this, the DAT process provides a schema for how prospective donors envision their recovery. Normalizing the importance of accepting care and of viewing recovery as a “marathon, rather than a sprint” are 2 features of this schema that are applied to each individual to assist in the decision-making process.

A material, but nonetheless important factor to consider is any effects that donation would have on employment and/or finances. Discussing the stability of employment and income, as well as the implications for being out of work for a period of several weeks to a few months, often allows the DAT members to show appreciation for the prospective donor’s choices and aids them in making an informed decision. Again, rather than simply considering the medical issues of being an organ donor, the DAT’s independent examination of these issues in partnership with prospective donors enables both a careful assessment of issues related to competence and a caring assessment of a person’s overall well-being. The donor always retains the power to decide to move forward, while the DAT retains independence in supporting or declining this decision, informed by the donor’s input.

The inclusion of psychologists in the DAT at the University of Virginia has aided the educational process. Typically the last provider with whom they meet, the psychological evaluation is a chance to assess what prospective donors remember about their educational experience, including information received from the donor coordinator, the written materials they have been provided, and any Internet research they have done. It is also a further chance to impart information, and repetition certainly increases the likelihood that prospective donors learn and retain new information. The psychologist’s evaluation affects decisions both by donors and about donors at the University of Virginia.4

Since 2001, 299 potential kidney donors and 69 potential liver donors have been evaluated through DAT at the University of Virginia. Among kidney referrals, 91 (30%) were declined: 72% due to donor or recipient medical concern, 21% after psychological evaluation, and 7% did not complete the evaluation process. Among liver referrals, 30 (43%) were declined: 78% declined due to donor or recipient conditions, 14% after psychological evaluation, and 8% did not complete the evaluation process.

The candidates declined after psychological evaluation included 10 with psychological or psychosocial concerns and 14 who decided to withdraw after the evaluation process. The psychological evaluation, using a Likert-scale from 1 = severe (unsuitable) to 4 = no concerns, identified contraindications in roughly 20% of candidates. The median score for 24 potential donors excluded by this evaluation was 2, whereas the median score for potential donors who were not excluded was 3. The reasons for the psychological exclusions included substance abuse, psychiatric diagnoses, and coercion. Individuals withdrew for a wide spectrum of reasons, including recognition of their own mortality, financial hardship, and ambivalence. Inclusion of the psychological assessment allowed our program to identify contraindications that might have been overlooked by conventional medical evaluation. This assessment may therefore augment the safety of the donor evaluation by including more thorough communication in the educational process.
Surgical Evaluation

Once approved by the DAT, the potential donor is contacted by the nurse coordinator, who assesses the donor’s desire to proceed with surgical evaluation. If there are specific recommendations that DAT has suggested the prospective donor consider or work on before proceeding, the nurse coordinator assesses the progress with those recommendations. The prospective donor next meets with a transplant surgeon, who reviews the imaging findings and then examines the prospective donor. The surgeon reviews at length the potential operative risks of donation as well as the potential outcomes for the recipient. The surgeon explicitly reminds prospective donors that undergoing this surgery is not medically necessary for them, will provide no medical benefit, and is not without risk. Specifically, risks such as organ failure, infection, bleeding, blood clots, and anesthesia-related risks are discussed. The risk of death (1 of 500 for liver donors and 1 of 4000 for kidney donors) is also clearly stated. Part of this surgical evaluation is again the reminder that, at any point, the prospective donor can withdraw his or her decision to proceed and have the transplant and donor teams’ complete support. As there is often a new perspective and set of information to consider, the donor evaluation process also requires the potential donor to observe a 2-week reflection, or cooling-off period. This cooling-off period is meant to be a procedural safeguard to ensure that an informed decision can occur without undue pressure, perceived or implied by the process itself. For many prospective donors, a cooling-off period does not result in a change in desired choice, but for others, this period has allowed further consideration and evaluation of potential risks. During the cooling-off period, prospective donors can contact the donor coordinator to voice any concerns, ask questions, or halt the process.

After the cooling-off period and before surgery, all patients have a standard preoperative history and physical examination and evaluation with the transplant surgeon. During this evaluation, the risks and potential outcomes of the surgery are again reviewed before getting the informed consent to proceed. The patients are also reminded, once again, that they can withdraw the decision to donate up to the point when they are anesthetized before surgery. Although this process strives to celebrate and encourage the positive and altruistic aspects of all individuals who bring themselves forward for living organ donation, curtailing the risk of foreseeable negative outcomes is also paramount to the ongoing safety and feasibility of this life-saving decision.

Conclusion

The central philosophy of the work with living donors at The University of Virginia is to maintain a practice of transparency to the greatest degree possible. The donor evaluation and educational process at the University of Virginia is an attempt to reach out to prospective donors in a way that is direct and based on a partnership model conducted “with them,” as opposed to “to them” or “for them.” In maintaining transparency, prospective donors are invited to be full partners in taking care of themselves and making the process work well. Risks, concerns, and decisions are overt and shared, rather than managed secretly. Information is shared, rather than merely providing a yes or no answer regarding candidacy.

This bidirectional educational process is the key to empowering prospective donors to make informed decisions (ie, fully informed consent) and assisting the multidisciplinary team in making appropriate decisions about prospective donors’ candidacy. By thoroughly employing independence, transparency, partnership, and advocacy, the education of the prospective donor and the medical team converge. Each donor is a public statement about living organ donation. Education, not just information, is a key to ensuring that the public perceives this process as fair, objective, supportive, and minimizing risk to the extent possible, which is paramount to ensuring the future of this life-giving process.

The evaluation of living donor education is an area of increased interest in the transplant community and a source for future research. Ongoing study in this area is needed, in particular, assessment of whether donors believe that they have been adequately educated. Such an assessment will aid in shaping educational efforts to meet the needs of prospective donors better. Although public perception is clearly important, it is feedback from prospective donors that should influence the approach to living donor education.

References
