

Independent donor ethical assessment: aiming to standardize donor advocacy

Living organ donation has become more common across the world. To ensure an informed consent process, given the complex issues involved with organ donation, independent donor advocacy is required. The choice of how donor advocacy is administered is left up to each transplant center. This article presents the experience and process of donor advocacy at University of Texas Southwestern Medical Center administered by a multidisciplinary team consisting of physicians, surgeons, psychologists, medical ethicists and anthropologists, lawyers, a chaplain, a living kidney donor, and a kidney transplant recipient. To ensure that advocacy remains fair and consistent for all donors being considered, the donor advocacy team at University of Texas Southwestern Medical Center developed the Independent Donor Ethical Assessment, a tool that may be useful to others in rendering donor advocacy. In addition, the tool may be modified as circumstances arise to improve donor advocacy and maintain uniformity in decision making. (*Progress in Transplantation*. 2014;24:xxx-xxx)

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Successful living donor kidney transplant between a twin pair served to expand the field of transplantation.¹ Living organ donation has become more common across the world as attitudes toward organ donation have evolved.²⁻⁶ Simultaneously, greater attention has been given to the identification, education, and consent process for persons volunteering to donate one of their kidneys to another person.

Informed consent constitutes the ethical standard for organ donation. To ensure an informed consent process, given the complex issues involved with organ donation, all transplant centers since 2007 have been required by the United Network for Organ Sharing and the Organ Procurement and Transplantation Network to have an

independent living donor advocate or to establish an independent donor advocate team (DAT) to represent the donor's interests. An independent donor advocate connotes a person not directly involved in the medical and psychosocial evaluation of the donor or the decision to provide a transplant to the recipient. The specific training or education for an independent donor advocate is not delineated, but each transplant center is allowed latitude to administer this responsibility. The independent donor advocate or advocate team assists the donor in obtaining and understanding information relating to the consent procedure, evaluation process, surgical procedures, as well as the risks and benefits of donation and the specific need for postsurgery follow-up.

Different transplant centers have approached the donor advocacy mandate with different strategies. Most programs have a designated person as donor advocate. Some centers prefer a team approach for a more comprehensive living donor advocacy.^{7,8} A survey of 120 transplant centers across the country revealed that nearly 83% of independent donor advocates are white women with a bachelor's or master's degree and professional training in nursing or social work.⁹ Responses to the survey's query about the responsibilities of the donor advocate varied. Most centers noted that promoting and protecting donor interests, donor education, evaluating donor willingness, and ensuring informed consent were important responsibilities for a donor advocate. Fewer centers reported that donor financial stability or family support, donor confidentiality, ensuring that donors know about other options, being a liaison to the transplant team, and facilitating donors' medical follow-up were also important responsibilities for a donor advocate.⁹

Most donor advocates were appointed; donor advocates volunteered for the position in fewer than 5% of transplant centers. Donor advocates were trained by the transplant team in most centers, whereas at other centers, the donor advocates were either part of the ethics committee or learned from lectures and/or training courses.⁹ Results of a recent quality improvement project done to evaluate the experience of donor advocacy among advocates and donors suggest a continued need to clarify the role of donor advocates.¹⁰ The United Network for Organ Sharing developed a proposal to standardize the role of the independent donor advocate on the basis of these findings and has submitted it for public review. That proposal further outlines the necessary training and education, role, and responsibilities of independent donor advocates.¹¹

In this article, we argue that use of a multidisciplinary and diverse team of volunteer advocates ensures a comprehensive consideration of the complex factors involved in organ donation. We outline the structure of the University of Texas Southwestern Medical Center (UTSW) DAT and describe the process of donor advocacy by which each potential donor is considered. In the process of advocacy, we present an objective method of donor approval, the Independent Donor Ethical Assessment (IDEA, see Figure 1), so as to remove as much bias as possible between donor decisions rendered by the team. Through our standardized process, the DAT simultaneously achieves a fair and uniform criterion for approval while promoting flexibility and sensitivity in the evaluation process.

The Donor Advocacy Team

UTSW adopted a team approach and formed the DAT in December 2007. The medical center's policy stated that the committee administering donor advocacy

would be made up of physicians, surgeons, psychologists, medical ethicists, medical anthropologists, former living donors, living donor transplant recipients, and a chaplain (University Hospital-St Paul Policy No. 4.0 Kidney and K/P Policies, Kidney, Liver and Pancreas Transplant Services, November 2007). The committee operates independently from the transplant team. The DAT at UTSW includes a licensed psychologist, who interviews the donor and performs a complete psychological evaluation of each medically approved candidate. The DAT draws on the expertise of members with diverse disciplinary, education, and experiential backgrounds. The current DAT includes 2 medical ethicists, 2 nephrologists, 2 urologists, a clinical psychologist, 2 attorneys, a community representative, 2 clergy members, a psychiatrist, a medical anthropologist, a living kidney donor, and a living kidney recipient. Appointed team members volunteer their time for the duration of their appointment, and this membership is neither exhaustive nor mandatory. What is unique about the DAT membership is its broad range of ethical, psychosocial, layperson, and medical input in rendering donor advocacy.

UTSW Donor Selection and Advocacy Process

Staff in transplant services at UTSW who are concerned with potential ethical and policy issues associated with transplant collaborate with the DAT to ensure adequate donor selection. Potential living kidney transplant donors initially undergo a 3-phase evaluation (Figure 2).

Level 1 is a clinical evaluation of the donor carried out by a clinical team of persons who are responsible for living donor evaluation as part of the transplant team. It involves simultaneous medical and psychosocial evaluation to determine the donor's suitability while the donor is being educated in various aspects of donor health and surgery, including short- and long-term risks, required postoperative care, the possibility of donor kidney rejection, loss, infection, and death of the recipient in the short and long course, insurability after donation, and available financial resources for continued health. These evaluations are done by transplant nephrologists, transplant surgeons, transplant social workers, and transplant coordinators. Information regarding the transplant process and procedure is given not only by verbal communication by each of the evaluators, but also through written pamphlets and brochures, and by video presentation. The donor is provided various opportunities during the medical and psychosocial evaluation to reflect on the purpose of donation and to opt out of the process at any time. At least 2 of these opportunities are given after the donor has been approved for donation by the DAT Committee and during the 2-week waiting period just before the surgery is performed.

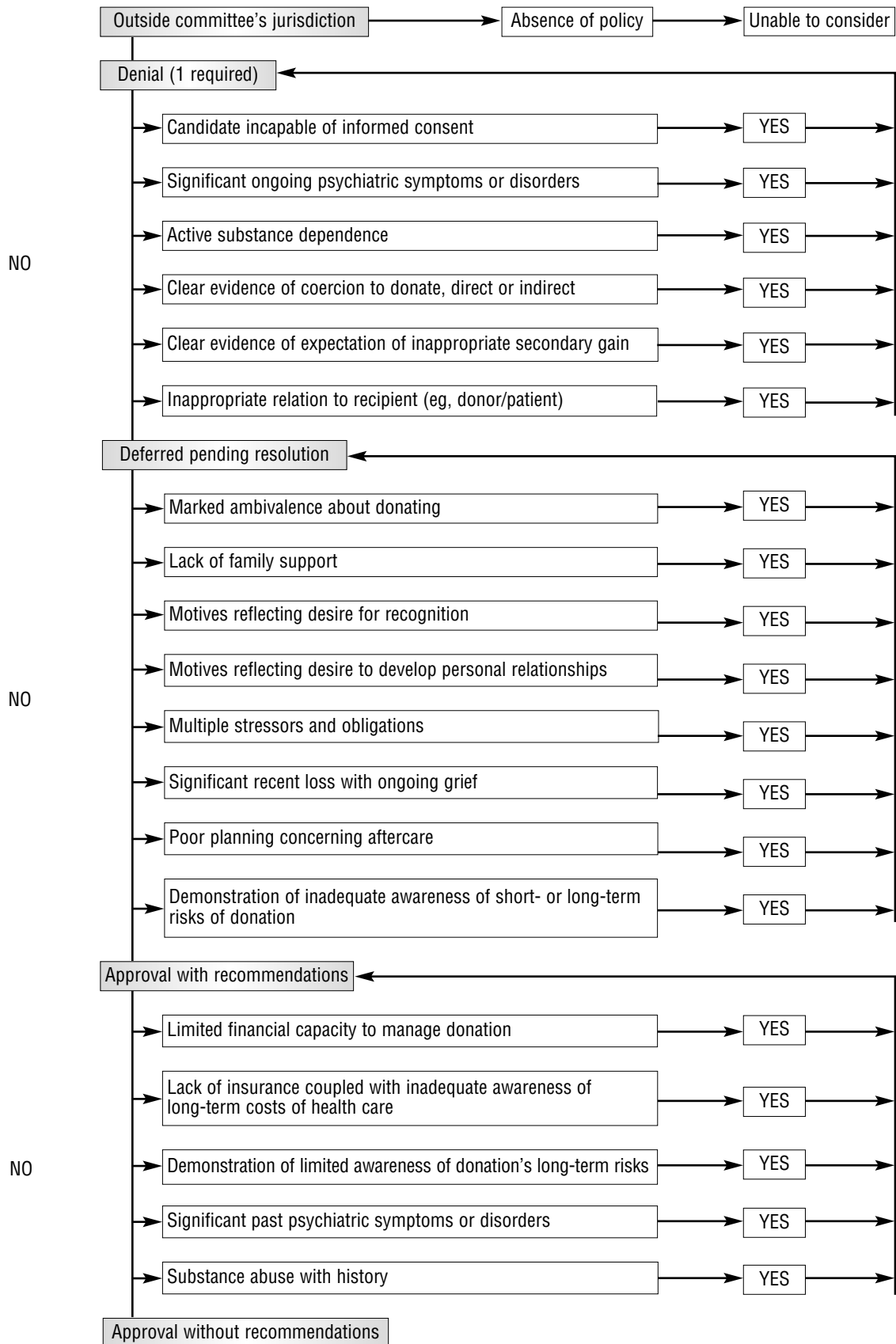


Figure 1 University of Texas Southwestern Medical Center's Independent Donor Ethical Assessment.

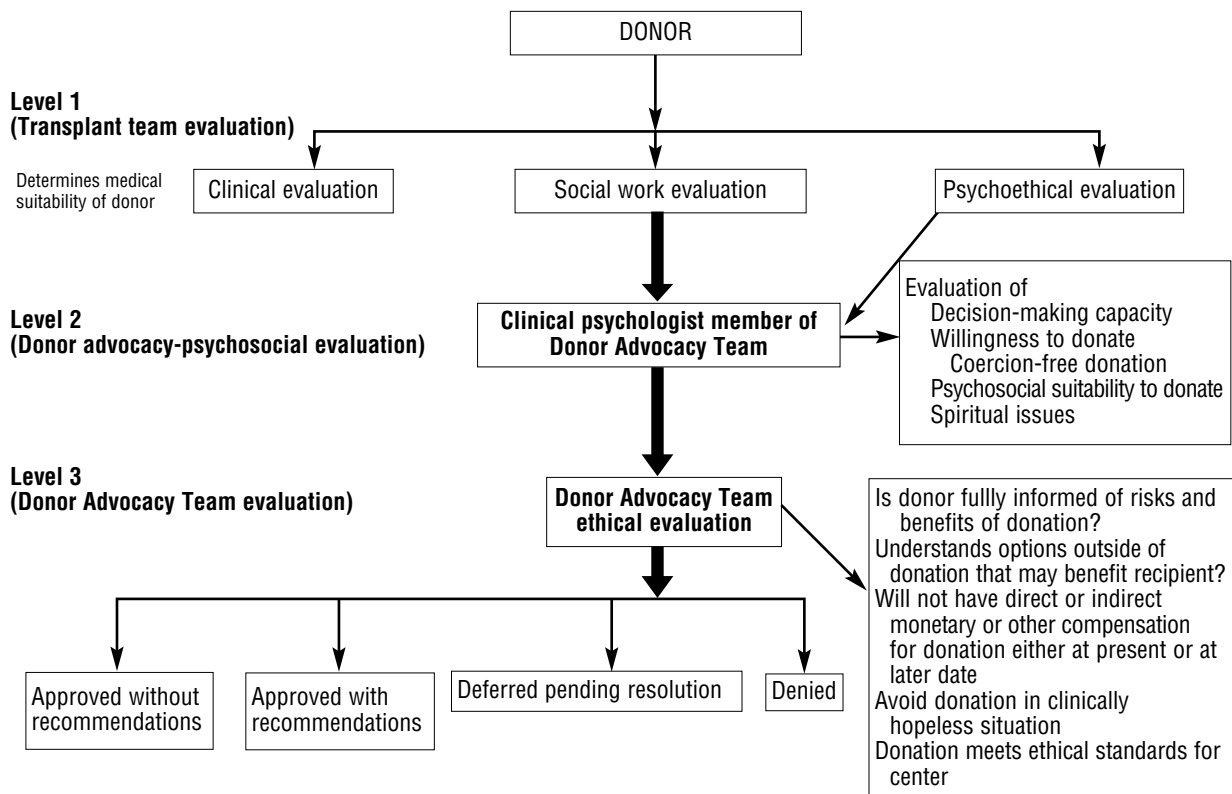


Figure 2 Process for evaluating donors.

Level 2 involves a formal psychological evaluation performed by the DAT's clinical psychologist to determine if the candidate is capable of informed consent. The required information is gathered through a clinical interview, the Mini Mental Status Exam, the Beck Depression Inventory II, and the Minnesota Multiphasic Personality Inventory-2. During the clinical interview, a donor candidate's knowledge about the donation process is assessed. Awareness of the risks involved with donation, possible outcomes for donors and recipients, plans for immediate and extended post-surgical care, financial capacity and planning to cope with donation, and information about expected benefits such as monetary compensation or gain in personal relationships or recognition are queried and uncovered. The ability of the donor to act rationally, the donor's willingness to freely donate, and any ambivalence regarding donation are also assessed during the clinical interview and the Mini Mental Status Exam. The Beck Depression Inventory II and the Minnesota Multiphasic Personality Inventory-2 provide information for the indirect assessment of the donor's rationality in decision making. A complete psychological and psychosocial assessment is then presented to the DAT.

Level 3 involves an ethical evaluation of the donor's candidacy by the independent DAT after the clinical psychologist team member makes a written and verbal

presentation of the psychosocial and psychological evaluation of the donor to the DAT. All DAT members then engage in open discussion about the donor encounter and assessment. The tasks of the DAT in donor evaluation include identification of potential psychosocial risks, assurance of the donor's understanding of risks and benefit of donation as well as their understanding of potential outcomes for donor and recipient, assessment of the donor's decision-making capacity, their ability to cope with surgery, their motives, as well as the potential for underlying compensation for organ donation.

The DAT reviews each case with particular attention to the consenting process to ensure the absence of coercion, guilt, misunderstanding of the donation, and undue pressure to donate, and the DAT reviews the donor's life circumstances (eg, substance abuse, family relationships, employment, obligations, health insurance or availability to continue long-term postoperative care, including a support system for recovery after donation). Subsequently, the DAT Committee uses the formulated IDEA algorithm (Figure 1) to deny, defer, or approve donation. If discussion indicates a further need for the donor to receive educational and/or therapeutic interventions before surgery, these recommendations are communicated to the transplant team (eg, counseling, access to medical care after surgery, health insurance).¹² Surgery is scheduled after approval is

obtained from the DAT and communicated to the transplant team.

The IDEA Algorithm

The IDEA algorithm corresponds to the DAT's decision tree and presents the criteria by which all donors' applications are evaluated. There are 3 decision options: denial, deferral pending resolution, and approval with or without recommendations. Figure 1 describes the specific criteria that are used to select 1 of the 3 decision options. Approval is recommended for those donor candidates who meet all the medical, psychosocial, psychological, and ethical requirements for donor candidacy. Additional recommendations may be sent along with the DAT approval if candidates have had significant past psychiatric symptoms or a history of substance abuse, or have limited financial capacity to manage the donation, or lack insurance to ensure at least 2 years of follow-up care. Such recommendations typically request additional counseling regarding follow-up care, including a plan for continued psychological or substance abuse support services, or other financial counseling.

After final approval, the DAT requires a 2-week waiting period before surgery. This waiting period may be shortened if the donor petitions to progress with surgery before the conclusion of the 2 weeks. The consensual decision is then conveyed to the transplant team in charge of donor evaluation for final donor disposition.

Strengths of the UTSW DAT

The multidisciplinary approach of an independent DAT and use of the IDEA algorithm provide a uniform approach to evaluation of donor candidacy. This team effort allows each member to advocate for the potential donor and to provide a particular perspective based on his/her expertise and experience. This process ensures a comprehensive evaluation of all aspects of the donor's concerns.

Although the DAT's clinical psychologist builds a bridge between the donor and the DAT, other members of the DAT do not interact with the potential donor. The ethicist member provides insight into the ethical obligations to maintain equity of the donation and that the process remains standard for all patients. Each member of the team provides his or her perspective, based on the team member's own discipline, of the donor's suitability. The attorney team member provides input to comply with current US law and transplant policies. The aim is to ensure that donor approval or denial remains free of bias toward particular individuals, undue hardship to a donor and/or donor family due to lost wages, received or perceived compensation, and links to medical tourism and organ trafficking, particularly in relation to donations from foreign nationals. Two other members of the DAT, a living

donor and a living recipient, speak to the experience of the donation process to balance concerns, clarify issues as may be seen by the donor and recipient, and highlight the altruism of live kidney donation. The anthropologist lends greater sensitivity to cross-cultural issues in both the patient's experience and in the provision of health care. The chaplain helps ensure sensitivity to spiritual issues within the secular context of medical care. As each team member's aspect is considered equally important so as to promote complete donor advocacy, the final decision is made collectively. Approval or denial is made according to a standardized process to avoid bias and ensure uniformity in DAT decision making for all donors being evaluated.

Strength of the IDEA

Use of the IDEA algorithm by the DAT was an attempt to address specifically the concerns expressed in the consensus statement of the Ethics Committee of the Transplantation Society outlined at the Amsterdam Forum promoting care of live donors and donor advocacy.¹³ In the process of donor advocacy, a team approach decreases individual biases that may exist in rendering decisions and representing donors' concerns. Collective decisions, however, can also lean toward bias if certain concerns are emphasized more than others. In order to avoid bias, the DAT integrated specific concerns leading to various decisions such as denial, deferral, and approval into the IDEA algorithm. The algorithm serves not only to help standardize decisions made by the committee but can be used to investigate and understand the process of donor advocacy more clearly. We anticipate that use of this tool will delineate areas for further education of living donors and treatment teams in regards to maintaining high standards of care for living donors.

Conclusion

Donor advocacy implies not only understanding the donor's perspective in organ donation but also being a representative for the donor to clarify the consenting process in relation to the donor's medical, ethical, and psychosocial composition. Therefore, a team composed of individuals with expertise in each of these aspects in addition to understanding the medical requirements of live organ donation may be the best suited to provide comprehensive donor advocacy. Appointed members of the uniquely composed independent UTSW DAT volunteer their time to collectively represent living donors by thoroughly reviewing the medical, ethical, and psychosocial aspects of donation in relation to each donor and rendering a decision for donation that is based on uniform criteria so as to avoid bias between each donor and decision. In this way, the multidisciplinary DAT serves to ensure informed consent similar to the role of an institutional

review board. However, it is also different from an institutional review board in that decision uniformity can be practiced given the similar circumstances of most donors. We think that this tool may be useful to others in rendering donor advocacy. Furthermore, it can be modified as new circumstances arise to improve donor advocacy and thus continue to maintain decision uniformity.

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