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REVIEW

How to increase living donation

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Summary

Living donation is the key to increasing access to successful solid organ transplantation worldwide. However, the means to expanding the number of living donors on a global scale are not known. Although there have been many suggestions for the best approach, cultural issues may limit the effectiveness of some strategies. Only a few ideas have been studied, and one in particular – outright payment to donors – may raise ethical issues that are difficult to surmount and might negatively alter altruistic behavior. With respect to the present environment, this article will describe some of the approaches that are being discussed to increase the number of living donors, with a particular focus on kidney transplantation.

Introduction

Living donation is the cornerstone of kidney transplantation worldwide and, in many areas, the key element in liver transplantation. Meanwhile, the need for kidney and liver transplantation is increasing. The best and most certain way to increase availability of donor organs for transplantation is to do so with the help of living donors. The challenge, however, is to increase living donation safely. Some efforts to increase living donation, such as making monetary compensation to the donors for their kidneys, involve the risk of slowing down organ donation for altruistic reasons on the one hand and, might also on the other hand, induce some of the prospective donors to withhold important medical information that they believe would jeopardize their chances of becoming a donor (and losing the monetary reward). Also because of concerns on possible exploitation that may take place on uninformed poor donors, the World Health Organization (WHO) earlier this year reaffirmed their commitment ''to the principles of human dignity and solidarity which condemn the buying of human body parts for transplantation and the exploitation of the poorest and most vulnerable populations and the human trafficking that result from such practices'' [1].

The main focus of this review is on living donor kidney donation. The scope is global. Articles included in this review were found by conducting a Pubmed search and a Google search using the phrases *living kidney donation, nondirected kidney donation*, *living liver donation*, *payment for donation*, *barriers and donation*, *disincentives and donation*, *World Health Organization and donation*, *transplant tourism*, and by evaluating the living donor presentations at the American Transplant Congress 2010 (May 2–5, 2010; San Diego, California). The goal of this review was to identify successful processes for increasing living kidney donation and evaluate strategies that are still under discussion.

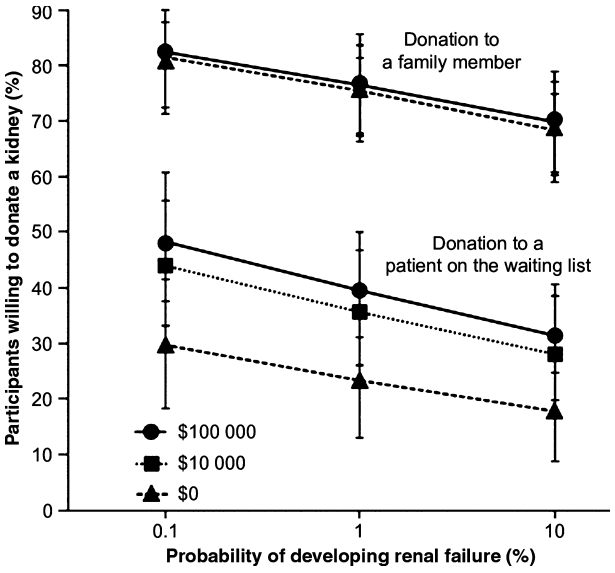

Figure 1 Adjusted proportions of participants willing to donate a kidney to family members and to patients on the waiting list as functions of payment and risk [5].

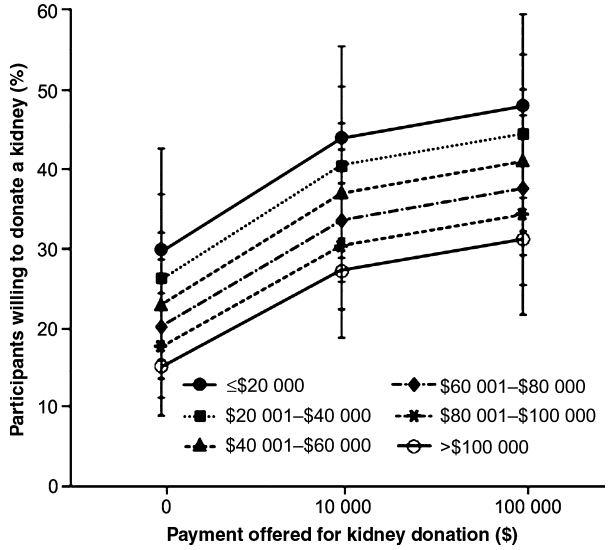

Figure 2 Adjusted proportions of participants willing to donate a kidney to a patient on the waiting list as a function of income and payment [5].

Factors that have increased living donation

Increasing living donation holds the key if survival probability of patients with end-stage renal-, also end-stage liver disease is to improve, especially with the increasing global rates of disease. Medical professionals and governments have realized this fact and have undertaken different approaches to increasing transplantation rates through living donation. Payment of living donors (incentives); media appeals on behalf of the sick; offers of medals; reduction of disincentives to donation by providing coverage of transportation and lodging; education of transplant candidates on ways to ask for living donors as well as the risks of donation; outright advertising by individuals on billboards, Facebook, YouTube, Craig's List; and websites specifically devoted to linking potential donors with recipients, such as Flood Sisters, matchingdonors.com and Living Kidney Donors Network, have all been either discussed or tried as methods for increasing living donation [2–16]. A survey of the membership of the American Society of Transplant Surgeons revealed that most members support payment for lost wages, guaranteed health insurance and an income tax credit as strategies to increase living donation [17]. Additionally, public meetings held by nontransplant centers, such as organ procurement organizations (OPOs), to explain the need for living donors and to prescreen potential living donors before referral to a transplant center, have helped expedite the process from identification of a potential donor to actual donation [18]. And it appears that focusing a transplant center's mission on living donation may increase the number of living donors. Several transplant centers have improved the effectiveness and growth in their living donor programs after encouraging the practice of having recipients present to evaluation appointments with friends and family thus extending the awareness of the issues involved in transplantation to more and more people.

More recently, the introduction of the concept of paired organ exchange or nondirected organ donation to an exchange list has markedly increased the number of living donor transplants [2]. However, before significant increases in donor exchange can occur in some nations, the potential participant donor cultures in a country must be assimilated into the country's general culture, and the idea of donation must be assimilated into conventional thought [2]. In the Netherlands, a review of participants in donor exchange programs and an analysis of partner (spousal) donations found that "the attitude and behavior of non-Europeans with the longest duration of stay in the Netherlands were closest to that of the Europeans" [2]. Foreign nationals with the shortest stay in the Netherlands participated the least in donor exchange or partner donation. Last, in Norway, some physicians take on the role of helping their patients find a living donor by calling potential donors identified by the potential recipient [4]. This approach was studied in the Netherlands by surveying prior and potential donors and recipients; it was determined that it would not work because of the degree of intrusiveness [19].

Stepping back and looking at what has been done may give the impression that there is no common thread in

the effort to increase living donation. However, increasing living donation may not be as complicated as it appears. What has likely helped more than anything to increase living donation? In two words, it is *story* and *education* [14,20–22]. People connect by hearing a story they can relate to. Individuals who listen with empathy to the history of those in need and who have a personality and predisposition that looks forward to help others are the kind of persons who step forward to donate to those whom they even do not know [23]. Recently, investigators in Kentucky appealed to preclinical medical students to join the National Marrow Donor Program [23]. Students were randomized to two separate appeal techniques. The first group received an appeal that was emotional and narrated a story of a donor and a recipient. The other group received a rational appeal highlighting statistical information about the need for stem cell donors and details about the donation process. More of the participants who received the emotional appeal (85%) said they would donate than those who received the rational appeal (49%) ($P < 0.001$). Thus, the first lesson in increasing living donation is to connect donors to patients through emotion, through stories.

Additionally, it is extremely important for transplant candidates to understand and support living donation. This is where education becomes critical. Many do not know the facts about the risks and long-term outcomes of living donation, and thus are afraid to engage others in a conversation that would lead to individuals considering living donation. Patients in need of transplants need to be educated in the risks of living donation. They need to understand the short- and long-term outcomes and the care available to living donors [22,24]. They need to know how to refer potential donors to sources of accurate information about living donation to help potential donors independently learn about the process. Potential recipients should not feel guilty about living donation. Over the last several years, surveys have been developed that help identify a specific patient's reluctance to accept living donation, and educational programs have been created that address patients' knowledge, needs, and fears. These are just now being rigorously tested [21,22]. Furthermore, primary care providers and nursing staff need access to resources to keep them up-to-date on living donor risks. To date, however, personal decisions by healthcare professionals about living kidney donation have not been proven to be impacted by formal educational courses [25]. And formal education also failed to increase high school student (17–18 years old) interest in becoming a living donor in Turin, Italy [26]. Although formal classes in transplantation may not sway the general population, education of potential recipients is the key factor so that they command the pertinent information about living donation in order to answer questions after they tell their story of need. Furthermore, transplant professionals asked to give talks on the importance of transplantation must be careful to include stories of real people, not just anatomy and statistical outcomes [20,21,24,27].

Education of potential patients is the key factor, as noted above. Culturally sensitive and personalized patient education is especially effective in enhancing the impact of education programs on increasing living donation [7]. In a randomized study of 132 patients (60 black, 72 white) approved for kidney transplantation at a single center, adding a home-based educational visit for the patient and their invited guests, given by transplant health educators who taught a standard clinic-based education program, increased the number of living donor inquiries, living donor evaluations, and actual living donor transplants. These home-based educational sessions were usually conducted by two educators, and visits to minority households were conducted by at least one minority health educator. The effect was greater in blacks than whites for living donor evaluations and transplants. Living donor kidney transplants were performed in 13.8% of black patients who attended the clinic-based educational session compared with 45.2% of blacks who received a home visit. The numbers were 42.5% and 59.4% for whites respectively.

Other approaches that have improved living donation have been advances in surgical techniques. The development of laparoscopic nephrectomy was a tremendous advance because it decreased disfigurement and reduced pain and time to recovery [28]. A recent randomized trial of laparoscopic verses open nephrectomy found that laparoscopic nephrectomy resulted in lower pain medication use, shorter length of stay, faster recovery and return to work, fewer pulmonary symptoms and fewer overall complications [28]. More recent developments include vaginal kidney extraction for female donors, further decreasing the scar sequelae [29]. Continued technical advances that result in reduction of pain, time off work, time away from important activities and visible scars should continue to increase living donation.

Removing disincentives to donation has the potential to increase living donation. There are many who cannot donate if their family expenses are not covered while they undergo evaluation, surgery and recovery [30]. Currently in the US, there is no general program to assist donors with transportation, lodging and loss of wages except for the National Living Donor Assistance Center [31,32]. Although very helpful, donors must meet eligibility criteria, including an income threshold of 300% of the Department of Health and Human Services Poverty Guidelines. This program does not cover all donors.

Globally, 21 out of 40 countries evaluated by review of government and ministry websites, legal databases and kidney, nephrology and transplantation foundations' websites were found to provide reimbursement for living donor expenses [33]. Another risk not addressed in the US is the guarantee of a donor's job following donation. Likewise, there is no guarantee that health insurance will be maintained.

Additional ideas in the literature that have not yet been tested but may offer an acceptable safety margin include offering other benefits such as paying for education, performing donor surgery during an elective surgical procedure such as cholecystectomy, engaging primary care providers as educators for their healthy patients who might consider living donation, and providing health insurance benefits to donors for life [29,34]. Not only have these ideas not been tested for their impact on donation, but they also have not been assessed as to their impact on donor survival or development of kidney disease.

Strategies that have not increased living donation

What has not worked to increase safe living donation? One strategy that has not worked is paying for living donation, at least, not the way it has been handled to date. Payment on an international scale has not been shown to improve living donor numbers or safety. Paid donors more often take risks with their own health and that of their corresponding recipients. They do not always reveal important details that may impact their health risk for transplantation, and the medical providers in this situation have often not performed thorough evaluations [35,36]. With paid living donation, the donor is essentially after the monetary goal [3], and the transplant center is after the money brought in by the recipient. The demographics of paid donors are different from that of the noncompensated donors. Paid donors tend to be male subjects, of poor socioeconomic status and have more co-morbid conditions (e.g., hepatitis C) [36,37]. Their post donation outcomes also tend to be poorer, and they are left without the resources to pay for the conditions and education that would keep them healthy. The families of paid donors are often worse off than before the donation [36,38–40]. Likewise recipients of organs from paid donors tend to do less well, with more rejections, more infections and higher mortality [36,39,41–43]. Countries reporting the results of paid living donors include the Philippines, Pakistan, Iran, India and China [3,35–37,39,44–47]. Even so, some authors continue to feel that if increased donation is not accomplished by nonfinancial means the black market in organs will increase [48]. Several transplant experts feel that financial or other incentives have not been rigorously evaluated in a setting with clear oversight and safety review and deserve further study [5,49].

What are the next steps?

The next steps should be to remove the barriers for living donors. Removing the hurdles to any goal will increase the likelihood of reaching the final target. Hurdles for living donors include lack of funding to cover their living expenses, travel, lost wages and the costs of care they provide to other family members [30,33]. Additionally, if there is no assistance available for postoperative care of the living donor by family or friends, donation halts. A mechanism is needed to provide assistance to potential donors who experience any of the hurdles to living donation. Whether it is a local, regional or national support system or financial resources, assistance should be available to all living donors in need. Employers should be able to accommodate employee requests to take necessary time off to donate organs. No matter the size of the enterprise, employers should encourage their workers who wish to become living donors. Living donation should not be something that only large companies can support.

Attaining a goal especially, if it involves change, also requires creating a sense of urgency around the activity. This helps to motivate and focus people to reach the intended outcome. A sense of urgency can be set by community and national leaders, as well as by engaging in community media events to tell the stories of those in need [8].

Asking people in primary healthcare settings about their willingness to become living donors is an untried method to increase living donation. Surveys have helped to delineate the profile of those who would consider nondirected donation [50]. Studies should be designed to query those whose profiles would identify them as willing to consider donation. If effective, then these surveys could be extended to the community at large.

Before we look backward to monetary incentives, we should look thoroughly at the issues detailed above. Although there is sentiment in some populations that remuneration may be acceptable, there would need to be careful study. And more than almost any other investigation, the study design, implementation and data management would need to be strictly overseen. The American Bar Association has published articles on the payment of living donors. One of these discusses the pros and cons of paying living donors, as well as possible approaches and payment options; overall, the paper advises open conversation inside and outside the transplant community [5,51] (Figs 1 and 2).

Conclusion

The means to increase living donation include teaching patients to tell their story, conducting media campaigns that include the stories of those in need, mounting community-specific campaigns that emphasize culturally important beliefs, expanding research on the long-term risks of living donation, especially in persons with minor medical abnormalities, creating surgical techniques that limit physical disfigurement, publicly celebrating the vital role of donors, providing healthcare coverage for the complications of living donation, passing legislation to guarantee that jobs will not be lost during the donation process, and enacting legislation to guarantee coverage of the costs of transportation, including lodging, lost wages, and child/elder care. Additionally, the community at large needs to receive continual education about the need for living donation, and the primary care community should have more information available about living donation to give to their healthy patients. All of this should be done before monetary incentives are once again placed on the table to encourage donation.

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