

Matnat Chaim ethical guidelines

Preface

The Matnat Chaim organization was established to encourage and facilitate kidney donations in Israel. The organization's sole goal is to alleviate the suffering of Israeli kidney patients awaiting life-saving transplants. The organization coordinates its activity with all Israeli hospitals that perform kidney transplants, and has facilitated hundreds of successful kidney transplants since its founding in 2009. The organization has also begun limited activity in the international arena.

With the growth of the organization and the expansion of its scope of activity, Rabbi Yeshayahu Haber, founder and chairman of Matnat Chaim, decided to formulate clear ethical rules that would define the criteria by which decisions are made. With a subject as sensitive as organ transplants, it is only natural that even a not-for-profit intermediary organization encounters difficult and complex ethical questions. In order to achieve uniformity and coherence in the decision-making process, and in order to ensure full public transparency, it was therefore decided to formulate and publish this document, as well as to establish an ethics committee to meet regularly and monitor the implementation process.

We hope and pray that we will succeed in our task and that our organization will serve as a worthy facilitator to bring the gift of life to hundreds of donors and recipients.

Introduction

The first kidney transplant reportedly occurred in 1954. Since then there has been widespread public debate regarding the various ethical aspects of organ transplantation. Participants include a wide range of thinkers and professionals, including doctors, religious leaders, philosophers and scholars (including experts in ethics and bioethics), statesmen, as well as ordinary citizens who have become involved in the subject and seek to contribute. On the one hand, the discussion focuses on the danger inherent in organ transplantation, and the possibility of the human body being seen as a source of "spare parts." The principle of the sanctity of the human body, whether we formulate it in religious terms or in universal moral terms, states that the human body is much more than the sum of its parts, and the possibility of organ transplantation should never cloud this assertion. On the other hand, we must address the difficult situation of the many patients waiting desperately for a transplant that will improve their quality of life and, in most cases, save them from premature death. In between, the ethical discussion touches on difficult questions regarding the determination of the time of death, the ethical rules governing transplant personnel - both doctors and administrators - and the ethical and practical questions of obtaining and allocating organs.

Our discussion of Matnat Chaim's activities does not require us to cover the entire spectrum of ethical questions regarding organ donation.

First of all, the starting point for discussion of the organization's activity is Israeli law, which firmly establishes guidelines on the major ethical questions. The State of Israel prohibits receiving payment for an organ taken from a person's body or paying for a transplanted organ (section 3a of the 2008 Organ Transplantation Law). This prohibition seeks to prevent the exploitation of low-income individuals who may be willing to suffer irreversible bodily harm in an effort to remedy their economic distress. The law does not accept the premise that organs are a commodity like any other that can be traded in a free market, and organ donation are therefore limited to donations from deceased donors or from altruistic living donors.

Second, since Matnat Chaim deals only with living kidney donations, the ethical considerations relating to transplants from deceased donors do not arise within the framework of the organization's activity. There is no need, therefore, to discuss the determination of the moment of death, nor other complex questions connected with deceased donor donation - such as the required degree of sensitivity towards the family of the deceased, versus the urgent need to save lives. In addition, since transplantation of the kidney does not pose a significant danger to the donor (except for the inherent danger of any invasive surgery performed under general anesthesia), there are no serious doubts regarding the ethics of donation; the risk to the donor is negligible when compared to the infinite benefit of saving lives, and the risks from the surgery itself are very low. Assuming that the donor is found fit for the operation, there is no need to question the ethical basis for the donation itself.

However, living kidney donation still raises many important ethical issues. In order to understand the specific ethical challenges facing Matnat Chaim, a brief overview of the nature of the organization's activities is in order.

Matnat Chaim – from the living to the living

The main goal of Matnat Chaim is to encourage kidney donation. The organization provides guidance and mentoring to volunteers who decide to donate a kidney. This mentoring activity supports the organization's basic goal of encouraging kidney donations, its *raison d'être*. Once the donor's decision is made, the forum through which the donation process is carried out (whether Matnat Chaim or the National Transplant Center, part of the Ministry of Health) is not of great importance. One of the ways in which Matnat Chaim succeeds in encouraging kidney donations is by allowing donors to state a preference regarding their recipient- a possibility that does not exist for those who donate through the National Transplant Center.

The issue of allowing living donors to donate according to personal preference has aroused some discussion among bio-ethicists in recent years. One article from 2006 says that "It seems unethical to allow potential donors to specify particular characteristics of the recipient (eg, age or race)"¹ On the other hand, others favored

¹ Vassilios E Papalois, "Ethical Issues in Living Donor Kidney Transplantation," *Experimental and Clinical Transplantation* (2006) 2: 485-497. See also: Patricia L. Adams, "The Nondirected Live-Kidney

allowing altruistic donors specify their preferences,² and even expressed doubt of the feasibility of sustaining a living kidney donation program if donors were not allowed to state preferences.³

The assumption behind Matnat Chaim's activity is that it is the right of a donor to choose the characteristics of a patient and to donate according to his preference. Often, if he is a match, a person will decide to donate a kidney to an immediate family member - spouse, child, parent or brother, and so on. This decision is altogether understandable, legitimate and appropriate, even if there are more urgent patients, and even if the likelihood of success would be greater in a different patient. It is the donor's right (and some might say: it is his obligation) to favor someone who is close to him. We all do this every day in many different contexts, and organ donation should be no exception. It is also possible that the personal story of a particular patient will touch the heart of a stranger, and that he will decide to donate to that kidney patient. It should be noted that in the past, altruistic contributions, with the exception of family members, were prohibited by law because of suspected trafficking in organs. Today, these donations are permitted, and are the basis of the Matnat Chaim's activities.

When a donor approaches Matnat Chaim and volunteers for a kidney donation, the staff will ask him whether he has preferences regarding the identity of the recipient. Some prefer to donate a kidney to a young person; some people want to contribute specifically to a man or to a woman. There are those who wish to donate to Jewish patients, and some have asked to donate to an Arab or Palestinian patient. Some will make a point of preferring a patient who is careful to maintain his or her health, such as a non-smoker. We have encountered dozens of other personal preferences, according to the subjective choices of each donor. As stated, our working assumption is that choosing the donor according to independent criteria is a legitimate choice, similar to giving charity according to the donor's inclination. A kidney donation is truly a "gift of life", and it is a donor's right to give his gift, a functioning kidney, to whomever he chooses.

Experience shows that the policy of allowing the donor to express his preference regarding the recipient significantly increases the number of kidney donations, and we therefore have no doubts regarding this policy, which serves our goal of saving as many lives as possible.

Anonymity

Donor: Ethical Considerations and Practice Guidelines," *Experimental and Clinical Transplantation* (2002) 74(4):582-9. All told, the discussion of this question is not widespread.

² For example, Spital A., Must kidney donation by living strangers be nondirected? *Transplantation* 2001; 72: 966; he suggests distinguishing between types of preferences and notes that allowing donors to specify preferences would definitely increase the number of donations to black patients.

³ See Broyer M, Affleck J., "In defense of altruistic kidney donation by strangers: a commentary," *PEDIATR NEPHROL* 2000; 14: 523-524

There are ethicists who believe that it is important to preserve anonymity surrounding living kidney donations⁴ Others add that in a “true” altruistic act, there is no need for the donor to know the identity of the recipient, and that the donation should be carried out in anonymous discretion. ⁵

Matnat Chaim’s policies do not endorse these positions. We believe that it is the donor’s right to see the results of the noble act of organ donation, and that it is the recipient’s right to express his or her gratitude directly to the donor. Our experience shows that kidney donation engenders a wonderful relationship between the donor and the recipient. We understand the concern that a relationship between the donor and the recipient may raise suspicion regarding compensation for the donation, and therefore do not reveal the contact details of the donor and recipient until the day of the transplant. But we are not prepared to deny the donor and the recipient the opportunity to experience this special relationship.

We also maintain that the possibility of developing this unique bond is itself one of the elements that encourages kidney donation, within the bounds of law and ethics, this is the primary goal of our organization.

Donor compensation

The issue of compensation needs to be touched upon in this document.

As stated above, the law prohibits any payment (monetary, non-monetary or other benefits) for donating an organ. On the other hand, sections 22-23 of the law provide for a uniform compensation that the state will pay to each donor to cover reasonable losses incurred from the donation process. This includes transportation costs, private medical insurance, psychological treatment, post-surgical rehabilitation costs and health insurance.

The state also provides for a non-uniform reimbursement of lost wages (section 22c) and free entrance to national parks and nature preserves (section 23b).

Matnat Chaim adds additional benefits. First of all, the organization will refund the costs of potential donors who are disqualified during the testing process. Sometimes the potential donor accrues substantial travel and other expenses but by law is ineligible for reimbursement from the government if he does not actually donate a kidney. Matnat Chaim reimburses these donors in order to encourage more potential donors to begin the testing process.

Following the surgery, Matnat Chaim offers assistance to the donor and his or family as needed - logistical help, prepared meals or babysitting. The organization also

⁴ Matas AJ, Garvey CA, Jacobs CL, Kahn JP, “Nondirected donation of kidneys from living donors,” N ENGL J MED 2000; 343: 433-476

⁵ Kaplan BS, Polise K., “In defense of altruistic kidney donation by strangers,” PEDIATR NEPHROL .2000; 14: 518-522

presents each donor with a small gift as a token of appreciation for their courage and selflessness.

We do not believe that any of the above raises significant ethical issues. The steps enumerated here aim to ease the burdens imposed by the donation process, and certainly are in accordance with the policy of encouraging life-saving kidney donations. We feel certain that nothing here constitutes inappropriate compensation.

Priority guidelines

Matnat Chaim acts as a mediator between the donor and the patient. The donor may begin the process with personal preferences - of course, there are many donors who choose to avoid any preference and seek to save lives without giving priority to a patient or group of patients - and the organization offers a potential recipient from their waiting list. The donor is not obliged to agree to the match offered by Matnat Chaim.

As opposed to donation through the National Transplant Center, the donor is not required to accept the recipient at the top of the list, and may reject for any reason the recipient that is suggested to him and request another recipient. Matnat Chaim will proceed with the donation process only once the donor has agreed to donate to the suggested recipient.

This process raises some complex ethical questions. While the final decision is left in the hands of the donor, the organization has significant influence on which patient will receive the transplant, and experience demonstrates that the first match suggested by Matnat Chaim is usually accepted by the donor.

In order to avoid ethical difficulties and ensure full transparency, it is necessary to establish clear criteria to guide the mediation process. There are a large number of possible criteria: the time the patient has spent on the waiting list; the likelihood that the new kidney will be absorbed and function properly in the donor; the urgency of the patient's medical condition; the patient's age; the varying health benefits that the transplant may bring, which differ from patient to patient; and many more.

Within such a complicated set of considerations, one criteria will often clash with another - for example, a patient whose condition is serious may have a lower chances of a successful procedure; on the other hand, there may be a patient whose condition is less serious but whose chances of transplant success are high – and difficult decisions are required. No matter how much we invest in upgrading the decision-making process, it is ultimately based on judgments, predictions and hypotheses that will never be perfect.

This is the situation we faced when we decided to formulate rules that would rank each patient listed on the organization's list, in this way determine the priority of patients waiting for a transplant. We recognize that the rank itself will not always accurately reflect reality, and that the final ruling may depend on ad hoc decisions by medical personnel, sometimes under heavy time constraints. Despite these reservations, and for the sake of maximum fairness and transparency, we decided to implement the ranking system detailed below.

In addition to the benefits specified by law, an organ donor who later needs a donation himself will receive priority on the list of patients waiting for a donation from the National

Transplant Center. This promotion is only natural: If those who sign donor cards and are prepared to donate organs after their death, receive priority on the waiting list, this is even more true for those who have already donated an organ while living. This principle is part of Matnat Chaim's policy, but it does raise some questions.

Should the donor's family be given priority?⁶ Should we distinguish between immediate family (spouse, children, parents and siblings) and second degree (uncles and cousins)? What about a person who functions in a life-saving capacity? Procedures must be in place to facilitate objective decision-making in each specific case.

Rank and waiting list priority

It is clear that the main ethical question that the Matnat Chaim needs to deal with is the question of waiting list priority. As stated above, the final decision regarding donation is made by the donor: he can accept the organization's proposal according to its policies or he can reject it and request an alternative proposal. However, most of Matnat Chaim's proposals are readily accepted by the potential donor, and therefore the organization must formulate clear rules to determine which patient will be proposed. Of course, these rules apply only after matching donors and recipients according to blood type.

For this purpose, we decided to adopt in part the ranking system used by the Ministry of Health to determine the order of patients on the transplant waiting list.

The principles of kidney allocation are detailed on the Ministry of Health website⁷, and some of the following policies are taken from there. We added criteria that take into account urgent medical conditions and prior kidney donations (by the patient or **first-degree** relatives). We also gave priority according to seniority on Matnat Chaim's waiting list and to length of time on dialysis.

Matnat Chaim's ranking procedure is based on the following:

- Length of time on Matnat Chaim's waiting list
- Length of time on dialysis
- Medical urgency of transplant
- Antibody level
- Previous kidney donation
- Inability of immediate family members to donate.

It should be noted that we did not take the age of the patient in to account, for two reasons. Firstly, many of our kidney donors wish to contribute to a young patient. In light of this fact, we did not see fit to give preference via our internal criteria to young patients, because that would give adults a double disadvantage - both by the donors' preference and by our own criteria. Another reason is the that the ethical consideration regarding age is not clear: is it ethical to give priority to a 15-year old over a 30-year-old with three dependent children? For these reasons we decided not to give priority based on age.

⁶ The National Transplant Center gives priority to immediate family of living donors.

⁷http://www.health.gov.il/Subjects/Organ_transplant/transplant/allocation_general/Pages/kidneys_allocation.aspx

We also did not include a genetic criterion – HLA compatibility – in our ranking system, as the National Transplant Center does. We do not have access to the genetic compatibility information and therefore did not include it in our considerations. Nevertheless, Matnat Chaim cooperates fully with the high-antibody databases in the transplant centers, and permits reassigning donors who match high-antibody patients.

Regarding waiting time, we divided this criterion into two categories. Length of time on the Matnat Chaim waiting list refers to the time from the first day the patient registered with Matnat Chaim. The second category is the length of time the patient has been on dialysis.

This double category gives an advantage to those who have been on the waiting list the longest, regardless of their dialysis status, while not ignoring those who have been on dialysis for a protracted period. On the one hand our policy enables those who have not yet begun dialysis to have a chance of receiving a transplant by virtue of their time on the waiting list. On the other hand, those who are suffering through difficult dialysis treatments are also prioritized.

Waiting time

Waiting time is calculated from the day the patient registered at Matnat Chaim. The ranking system is a linear progression from 0 points at the time of registration up to a maximum of 6 points after 144 months of waiting time. Each month the patient receives 0.04 points.

Length of dialysis treatment

Length of dialysis treatment is calculated from the time the patient began dialysis. The ranking system is a linear progression from 0 points at the time of registration up to a maximum of 6 points after 144 months of dialysis. Each month the patient receives 0.04 points.

Urgency of transplant

Both in Jewish tradition and in universal morality, human life is the supreme moral value. As stated in our ancient texts, "Nothing is more important than saving lives" (Tosefta, Shabbat 9:22). It follows that when a person is found (in the opinion of medical specialists) to be in a life-threatening situation, he should be given first priority on the list of those awaiting a transplant. This consideration is binary: if the risk is imminent, the patient will be promoted to the top of the list. If there is no imminent danger to life, no preference will be given to the severity of the suffering - a consideration that is too subjective to include in the list of criteria.

Antibody levels (PRA)

Some patients waiting for transplants have a high antibody level. This means that their body produces antibodies to many potential donors, and their chances of finding a compatible donor are low.

In order to increase these patients' chances of finding a match, we keep, in coordination with the databases of the transplant centers, a separate waiting list for patients with high antibody levels (over 75%), and if a match is found for them they are immediately given priority over other patients. We do not give high-antibody patients extra points, as they do in the National Transplant Center. Should an appropriate donor be found for one of these patients, they are treated as an especially urgent medical case, since if they are passed over they may have to wait many more years to find another compatible donor. This is the reason we have decided to have a separate list for high-antibody patients and not simply give them additional points.

Living kidney donors

As mentioned above, it is inappropriate for someone who donated one of his kidneys to have to wait in line for a transplant like everyone else. Matnat Chaim gives priority to the kidney donor himself and to first-degree relatives (parents, children, spouse, siblings).

Testing of family members

If the kidney patient or his or her relatives are unwilling to have first-degree relatives tested for a possible donation, four (4) points will be deducted. Although the patient should not be "punished" for the actions of others, this mechanism is designed to encourage close relatives to donate kidneys to their loved ones so that unrelated altruistic donors can be assigned to patients who have no relatives who can assist them.

Exceptions

In addition to the guidelines set down in this document, there may be exceptional cases which justify advancing a patient to the top of the list, such as the example above of a surgeon who is needed to save lives. In all such exceptional cases, Matnat Chaim's staff members will present the information to the exceptions committee, who will make the decision on advancing the patient to a higher spot on the list.

The Ethics Committee

Because of the extreme sensitivity involved in organ transplants and because reality is often more complex than written guidelines can reflect, Matnat Chaim has established an ethics committee that meets every other month to review the organization's activities from an ethical standpoint. The committee consists of a rabbi who serves as a rabbinical court judge, a legal expert (a lawyer with an advanced degree) and a medical specialist. The committee has free access to all of the information available in Matnat Chaim's databases and will make recommendations to the organization both regarding ethical guidelines and specific cases.

The ethics committee will also serve as the exceptions committee, as mentioned above.

Summary

"I have set before you life and death, blessings and curses. Now choose life, so that you and your children may live." (Deuteronomy 30:19) Our Torah gives life, we live according to G-d's favor – and we are asked to choose life.

Matnat Chaim is one of the rare organizations whose daily activity revolves around life itself – saving lives and immeasurably improving quality of life. It is a tremendous privilege to deal with such meaningful matters, but also a terrible responsibility which leads to great stress and many sleepless nights.

These guidelines are designed to ease the burden on those who make life and death decisions and to ensure that they faithfully fulfill their responsibilities to make fair and just allocations.

We pray to undertake these questions of medicine and of life in with honesty and devotion and to be found worthy of divine guidance, without which our efforts will come to nothing; and that via our kidney donors we may bring a true "gift of life" to the many patients who are in need.