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ARTÍCULO

The case for making organ transplant waitlists public to increase donation rates: is it possible?

Hacer públicas las listas de espera para aumentar la donación de órganos: ¿es posible?

Fer públiques les llistes d'espera per augmentar la donació d'òrgans: es possible?

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Abstract

This paper reviews the close connection between unwillingness to donate and a perception that organ allocation is driven not by medical need but by ostensibly unfair factors, such as status, income, ethnicity, or connections. The lack of organs for transplantation is one of the biggest hurdle facing transplantation systems worldwide and transplantation is the only technologically advanced field of medicine that is totally dependent on public understanding and support and that provides strong reasons to increase transparency and make waiting lists publicly available.

Keywords: transparency; organ transplant waiting lists; organ donation.

Resumen

Este artículo revisa la estrecha relación que ha sido observada entre la negativa a donar órganos y la percepción de que los mecanismos de asignación no están, siempre, motivados por la necesidades médicas, sino que por factores aparentemente injustos como el estatus, los ingresos, el origen étnico o las conexiones. La falta de órganos para trasplante es uno de los mayores obstáculos que enfrentan los sistemas de trasplante en todo el mundo y el trasplante es el único campo tecnológicamente avanzado de la medicina que depende totalmente de la comprensión y el apoyo público, lo que ofrece fuertes razones para aumentar la transparencia y la confianza de la comunidad haciendo las listas de espera públicas.

Palabras clave: transparencia; listas de espera; donación de órganos.

Resum

Aquest article revisa l'estreta relació entre la negativa a donar òrgans i la percepció de que els mecanismes d'assignació no sempre estan motivats per necessitats mèdiques, sinó per factors aparentment injustos com són l'estatus, els ingressos, l'origen ètnic o les connexions individuals. La falta d'òrgans per a trasplantaments és un dels majors obstacles que han d'afrontar els sistemes de trasplantament a tot el món i el trasplantament és l'únic camp tecnològicament avançat de la medicina que depèn totalment de la comprensió i el suport públic, la qual cosa ofereix fortes raons per augmentar-ne la transparència i la confiança de la comunitat fent que les llistes d'espera siguin públiques.

Paraules clau: transparència; llistes d'espera; donació d'òrgans.

Introduction

“Transplantation is the only technologically advanced field of medicine that is totally dependent on public understanding and support, for without donors and recipients transplantation would simply not exist. Any changes that alter the perceived fairness of the system could have an important negative impact”¹.

A lack of organs for transplantation is one of the biggest hurdles facing transplantation systems worldwide. In the United Kingdom, every year more than 500 patients died while on the active waiting list for an organ transplant². The gap between the number of persons on the national waiting list and the number of available organs increase every year, like the number of people dying each year for want of a solid organ transplant³. Every day, 30 U.S. citizens die from the failure of a vital organ while still waiting for a suitable transplant, and similar figures—relative to population size—are reported from all of the other developed countries⁴.

Options intended to improve organ donation rates have proved insufficient. There is a need to focus on innovative solutions and strategies to increase organ donation that are likely to succeed in the short to medium term. One alternative is to battle the bad reputation of the system due the impact of some trigger events that, from time to time, occur in almost every country in the world (as discussed below). This is important because while the extent of opaqueness varies with the specific culture and degree of governmental and health legislation development, most motives argued to *opt out* of organ donation can be traced back to myths about critical patients failing to receive safe, proper care and mistrust in organ allocation procedures⁵.

We know that paucity of information on how waiting lists are managed and limited resources allocated is all too common across most fields of medicine. But organ transplantation is front and center among areas. We argue here that organ transplantation provides a strong case for departing from the right to confidentiality in the form of publicly-accessible waitlists⁶ designed to fight the shortage of organs for transplantation⁷.

1. The Issue: Who gets the organ available for transplantation?”

“There are many frameworks within which organ transplantation can operate, but at the heart of any system must be trust... Patients in need of a transplant must be able to trust in an ethical and fair organ supply, and that their doctors will provide the highest standards of clinical care”⁸. In Chile, Organs become public goods after being donated for transplantation to be distributed by relevant

agencies on behalf of the State. The Organ Donor Act (Law 20413, 2010) established a presumed consent system and a transplantation coordinating committee, required the Office of Vital Records to keep an official non-donor registry comprising all individuals who opted out. Even though there have been several legislative reforms in order to increase organ donation, the shortage remains. Why?

Mistrust in the organ allocation system is the leading motive asserted by opt-outs⁹. In recent years, some high-profile cases (expeditious transplants for interior minister Edmundo Pérez Yoma and the wife of health minister Jaime Mañalich) have done little to dispel this perception. Recent studies find that nearly 70 percent of respondents are opt-outs, citing an “opaque” organ allocation system. Fallout from the above cases, compounded by general mistrust in the system, led to a precipitous drop in donation rates¹⁰.

Transplant centers in the UK are required to meet agreed clinical standards, including these patient selection and organ allocation policies¹¹. The criteria for selection and allocation of a donated organ must be objective and the reasons evidence-based where possible¹². Still, approximately 1000 people are dying each year on the UK for want of a solid organ transplant¹³. In these contexts, some events that have been an important impact on public perception of organ donation need to be fought with transparency. In 1990, Raymond Crockett was found guilty of procuring human organs from live donors in exchange for money, as part of a “kidneys for sale” fraud¹⁴.

In the United States there is a legal federal mandate that the allocation system must take into account both efficiency and equity¹⁵. The United Network for Organ Sharing (UNOS) sets the principles for allocation of scarce organs and creates formulas for allocating them. Whenever an organ becomes available, a computer generates a priority list among all eligible patients awaiting a transplant¹⁶. Yet, several conspicuous cases have also put public faith in the allocation system to the test. In the nineties, basketball star Mickey Mantle received a swift liver transplant even though his kidney failure was alcohol-induced and he had inoperable cancer. As he bypassed over 4,000 others on the organ waitlist, charges of favoritism were levelled at the system¹⁶. In 1993, Governor Robert Casey received a heart-liver transplant in less than a day of going on the list. In 2002, Vice-president Dick Cheney received a heart transplant at 65. Recently, Apple co-founder Steve Jobs secured a liver transplant posthaste, even though he had terminal cancer and little chance to recover¹⁷.

In 2012 it came to light that some German university hospitals had either manipulated the laboratory values of patients on the waiting list or forged hemodialysis data to increase the Model for End-stage Liver Disease MELD. There also were accusations of internal non-transparency, as other physicians in the same center claimed to have had no knowledge of the data transmitted to Eurotransplant¹⁸. Organ donation dropped 12.8 percent from a year earlier throughout Germany

and reached a record low since 2002. The decline was most noticeable in the second half of 2012, as the manipulations of the three transplantation centers became public¹⁹.

Non-transparency in organ allocation fuels skepticism about system fairness, and given the close link between public perception and organ donation, bad publicity has an obviously adverse impact on the system as a whole²⁰. Research also shows a close connection between unwillingness to donate and a strong belief that organ allocation is driven not by medical need but by ostensibly unfair factors, such as status, income, ethnicity, or connections²¹. Donation depends on a positive perception of the allocation process.

2. Organ Allocation: Who decides?

The lack of transparency in the allocation criteria has fostered community skepticism regarding the fairness of the organ allocation process. Organ donation is a field in which public opinion holds significant sway²². Public perceptions are often unfavorable, with organ allocation systems frequently associated with events suggesting interference by criteria at variance with health needs and distributive justice²³. In these contexts, the actual strategies to increase the availability of organs cannot ignore the need for more transparency.

The Madrid Resolution and Prospects for Transnational PIAs required governments to ensure appropriate access to safe and ethical transplantation with special attention to maximizing donation from deceased donors and to protecting the health and welfare of living donor in a *national self-sufficiency* new paradigm²⁴. The trouble with these resolutions lies in expecting substantial improvement in donation rates based on *the same old standards*. Governments are asked to enact policies capable of improving self-sufficiency and augment organ availability while upholding the WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation, which make guarantees of increased system transparency contingent on the rule that “the anonymity of donors and recipients be maintained”²⁵. In our view, it is difficult to maximize donation while maintaining the same anonymity rules.

Principle 11 of the WHO Guiding Principles on Human Cell, Tissue and Organ Transplantation requires the organization and execution of donation and transplantation activities, as well as their clinical results, to be transparent and open to scrutiny, while ensuring that the personal anonymity and privacy of donors and recipients are always protected. The WHO feels that the transparency requirement “is not inconsistent with shielding from public access information that could identify individual donors or recipients”²⁵. But as noted, the research tells

a different story. Even if “the necessity of traceability” is upheld, the fact of the matter is that the opt-outs we wish to turn into opt-ins (if present rates are to improve) lack the tools needed to know why a certain person received an organ. What’s more, even individuals on organ waiting lists express reasonable doubt about the fairness of allocation decisions²⁶.

Confidentiality runs counter to a patient’s interest in receiving the best care possible²⁷. To such patients, best care means obtaining a new organ. Inasmuch as mistrust in allocation systems directly impacts availability of organs for transplantation²⁸ bringing waitlists into the open should afford patients a chance to more closely monitor the procedure while encouraging others to trust the system and consider becoming donors. We argue here that organ transplantation provides a strong case for publicly-accessible waitlists²⁹.

In cases such as organ allocation, confidentiality may clash with a patient’s interest in receiving the best care possible. “Allocation rules, defined by appropriately constituted committees, should be equitable, externally justified, and transparent”, Guiding Principle 9²⁵. Yet, transparency and accountability demands cannot be met solely by ensuring that “every step in the allocation process is documented and can be explained”³⁰.

Reinstalling confidence in the system requires a complete overhaul of allocation mechanisms, ensuring a transparent process across the board and public involvement in setting the criteria that will ultimately determine who stays alive. What really matters is to provide, as needed, the ability to track waitlist progress, the criteria under which a given patient is allocated an organ, and where waiting relatives, friends or acquaintances stand. In this line, the discussion should focus on what are the best mechanisms to ensure full transparency of the system or organs allocation.

3. Discussion: A Public Waiting List?

In general, the goal of all these allocation systems is to harmonize and articulate justice as well as utility, at last, in three factors: present need, urgency and efficiency. However, the integration of these goals into a single formula is a formidable task that no current system has really achieved. The reason why it is not enough to just explain patients about the selection criteria of the waiting list is that transparency's aim must continue throughout the process. Patients have the right to know why they have not been chosen yet for transplantation. Especially if certain disrepute events have undermined the public perception of fairness.

To be sure, the general principles of distributive justice cannot address critical rationing issues through decisions leaving no room for divergence. Real transparency requires parsing the value-based issues often passing for clinical judgement. As such, a fair process requires according individuals the ability and tools to challenge medical decisions –including, first and foremost, information—. Studies show that knowing “who received an organ, and why” is a crucial requirement not met by merely reporting a procedural result. Stakeholders should have the ability to know exactly who is on the list, how the process is unfolding, how the rules previously determined by all were applied, and if concerns arise, to contest decisions²⁸. At present, health systems lack mechanisms ensuring transparency –in general, not just on issues of transplantation³¹—.

Surely, some fear that bringing allocation criteria and procedures into the open could compromise the perception of “rationality” of the allocation systems because most of the systems cannot really integrate in a singular formula all of the goals that a fair and efficient allocation system needs to aim “integrating these goals into a single formula is a formidable task”¹⁶. But if patients are to accept the limitations imposed by organ shortages, they need tools to commit to these compelling reasons as well as clear grounds to dispute them. That is why transparency is so important. The transparency imperative cover many ideas: (i) transparency of allocation algorithm (which is publicly available for some current systems), (ii) transparency of waiting lists (which encompasses removal of anonymity), (iii) public involvement in modeling allocation algorithm and (iv) ability of potential recipients to challenge allocation decisions³¹. We claim that all of these elements must be public access. Therefore, the discussion from now on should not be whether to be fully transparent, but which are the best mechanisms to ensure such transparency.

The reason why it is not enough to just explain patients about the selection criteria of the waiting list is that transparency's aim must continue throughout the process. Patients have the right to know why they have not been chosen yet for transplantation. Reinstalling confidence in the system requires a complete overhaul of allocation mechanisms, ensuring a transparent process across the board and public involvement in setting the criteria that will ultimately determine who stays alive (particularly because the allocation criteria usually have not been agreed with the community involvement)³³. What really matters is to provide, as needed, the ability to track waitlist progress and the criteria under which a given patient is allocated an organ³².

There are many factors that influence the increase of organ donation rates, including potential donor availability, transplantation infrastructure, health care spending and public attitudes, as well as familial consent and donor registries. Nevertheless, without transparency, open discussion and appealable decision-making, organ donation rates will not improve substantially. Too much is at stake not to commit to a concerted effort to overhaul system design. Unless the rules change, results will stay the same.

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