Re-evaluating the Recipient Criteria for Organ Transplants

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Recently, a subspecialist at a well-known children’s hospital communicated to the parents of a 3-year-old girl with Wolf-Hirschhorn syndrome, a rare genetic condition that, in her case, included considerable cognitive disability, that she would not receive transplantation because of her intellectual deficit.

Soon after, in the face of national media attention — much of it negative — the institution issued a statement indicating that intellectual ability was not a factor in its program’s transplant eligibility decision-making process.

ORGAN SUPPLY AND DEMAND

Solid organ transplantation has always been wracked with the problem of too much demand and not enough supply. This scarcity results in allocation procedures that inevitably exclude some possible transplant candidates. The Wolf-Hirschhorn case prompts reconsideration of ethically justifiable criteria for deciding who will get an organ when not all can have them.

There are three main points to consider:
1. Who should make organ allocation decisions?
2. On what basis can we say organ allocation is fair and defensible?
3. Should we think differently about deceased-donor organ transplantation compared to transplantation of organs from a living donor?

Decisions about organ transplantation made by individual clinicians have the greatest likelihood of bias — whether it be unconscious or deliberate — against patient or family characteristics. As the Stanford-based survey indicated, institutional transplant programs exhibit a wide variation in who they will agree to list for deceased-donor organs.

One might say that government entities, with obvious responsibility for good stewardship of public resources, have the strongest claim to authority to make organ allocation decisions. However, governments have acted with unjustified bias in the past: witness legal segregation of racial and ethnic groups in the US, South Africa, and elsewhere; or ethnic and religious discrimination — and worse — in Nazi Germany, contemporary China, and the Sudan, among other places. Social policy, even when generated in places with democratic processes and various political checks and balances, does not guarantee fairness.

ALLOCATION DECISIONS

In 2009, a regional authority in northern Italy indicated that patients with IQs below 50 would not get solid organs; an IQ of between 50 and 70 was made a relative contra-indication to transplantation.

So, sometimes individual clinicians make these decisions, sometimes transplant programs make them, and sometimes a political entity makes the decision. The question is whether or not this matters.

Other transplant programs have made, and continue to make, decisions about listing patients for deceased-donor organs using a variety of psychosocial factors, including intelligence.

FAIR AND DEFENSIBLE CRITERION

One could argue that the most important criterion for who should have access to deceased-donor organs is the likelihood the transplant recipient will benefit. But not everyone agrees on what constitutes a benefit. For some, the opportunity to continue life in and of itself warrants a chance to live on, regardless of the ability of the individual to have conscious enjoyment from his or her existence.

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Some proponents of this view, we can call them “vitalists,” argue that we cannot know for certain what kind of mental processes those with profound cognitive disability have. Others view continued cellular function alone as a gift from God that humans have an obligation to support if at all possible. Skeptics should recall the Terri Schiavo feeding tube removal debate, which reached the floor of the US Senate and the chambers of the US Supreme Court.

No arguments based on rationality alone can definitively refute the positions of those deeply committed to vitalist beliefs. In the US, according to polling data, 15% to 20% of the population holds vitalist views. No matter one’s perspective on whether a majority should be sufficient to impose rules for allocation of scarce resources, few politicians welcome such a fight.

Even if a public or quasi-public authority, like the United Network for Organ Sharing (UNOS), which helps administer the organ distribution system in the US under a charter from the federal government, would take on questions relating to transplant eligibility and cognitive disability, it is likely UNOS’ policymakers would have a hard time reaching consensus on what level of impairment would justify denying organs to individual patients. Would they agree to exclude those in a permanent vegetative state or a minimally conscious state?

LIVING- VS DECEASED-DONOR DONATIONS

It is possible, even probable, that many who oppose the use of deceased-donor organs for patients with profound cognitive impairment would not object to living-donor organ donation. However, even this does not seem completely straightforward.

Some clinicians, especially surgeons responsible for removing kidneys, liver segments, lungs/lobes, and segments of intestines or pancreases, might object to putting donors at risk for patients who do not qualify for deceased-donor organs. Some clinicians would look at parents willing to donate and hesitate; surgeons could reasonably worry about placing parent-donors at risk of death or serious morbidity, particularly if there are other children to support. Many would have qualms about organ donation from healthy minor siblings to treat a brother or sister with serious intellectual disability.

Nevertheless, a Japanese group in 2006 reported a series of 25 kidney transplants (23 from parental donors, two using cadaveric kidneys) in “patients with more severe or profound mental retardation than in former studies.” The grafts were all functioning at a mean follow-up of more than 3 years and “…all persons providing primary support for patients were satisfied with the [kidney transplant] and believed that quality of life was improved in both transplant recipients and themselves.” Those physicians and surgeons felt comfortable with the requests to transplant cognitively impaired patients.

Whether such medical success constitutes a wise use of social resources — though transplantation typically costs less over years than ongoing dialysis — will continue to be the subject of heated debate for some time, or until health care expenditures simply overwhelm the US economy. It seems clear we have no universally accepted moral basis for settling these disputes.

REFERENCES