

Review

Clinical review: Moral assumptions and the process of organ donation in the intensive care unit

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Abstract

The objective of the present article is to review moral assumptions underlying organ donation in the intensive care unit. Data sources used include personal experience, and a Medline search and a non-Medline search of relevant English-language literature. The study selection included articles concerning organ donation. All data were extracted and analysed by the author. In terms of data synthesis, a rational, utilitarian moral perspective dominates, and has captured and circumscribed the language and discourse of organ donation. Examples include "the problem is organ shortage", "moral or social duty or responsibility to donate", "moral responsibility to advocate for donation", "requesting organs" or "asking for organs", "trained requesters", "pro-donation support persons", "persuasion" and defining "maximising donor numbers" as the objective while impugning the moral validity of nonrational family objections to organ donation. Organ donation has recently been described by intensivists in a morally neutral way as an "option" that they should "offer", as "part of good end-of-life care", to families of appropriate patients. In conclusion, the review shows that a rational utilitarian framework does not adequately encompass interpersonal interactions during organ donation. A morally neutral position frees intensivists to ensure that clinical and interpersonal processes in organ donation are performed to exemplary standards, and should more robustly reflect societal acceptability of organ donation (although it may or may not "produce more donors").

Keywords ethics, intensive care units, language, organ donation, persuasive communication

Introduction

The great majority of intensivists are supportive of transplantation and organ donation [1]. We often care for organ transplant recipients and are well aware of the benefit that these patients derive from transplantation [2]. Transplantation results continue to improve (despite increasing case complexity) and this success has driven demand for organ transplantation. At the same time, the number of organs available for transplant has increased comparatively less. Consequently, as waiting times of potential recipients lengthen and some recipients die before transplantation, transplant professionals increasingly describe this tragedy as "the organ donor shortage" and vociferously advocate for changes that might "increase the number of organ donors" (including live-donor transplantation, which I will not discuss here).

Historically, discussion of organ donation with families of potential donors was performed by transplant professionals, often nephrologists, who were introduced to families by intensivists after brain death had been confirmed and the family had been informed of the fact of death. Responsibility for holding this encounter is now vested in trained 'designated requestors' (often 'organ procurement coordinators') in some countries [3], and in intensivists in others [1]. The present review examines the moral assumptions that underlie this encounter and discusses two different approaches that I have termed 'utilitarian rationalism' and 'moral neutrality'.

Utilitarian rationalism views the encounter as being part of transplant organ procurement, driven primarily by the needs of transplant recipients and, secondly, by any positive views about organ donation previously expressed by the now-

deceased. The desired outcome in this paradigm is organ donation.

Moral neutrality views the encounter as being part of end-of-life care in the intensive care unit (ICU), driven by the needs of the donor family and by the principles of informed consent. It encompasses discussion of all relevant issues (including any views about organ donation previously expressed by the now-deceased) but the desired outcome is good process (which may or may not include organ donation).

Methods

A search of Medline from 1980 until February 2004, limited to articles published in English with abstracts, was undertaken using the search strategy 'intensive care' and 'organ donation', (the latter term maps within MeSH® [Medical Subject Headings, National Library of Medicine, Bethesda, MD, USA] to "organ procurement", *vide infra*). The search was limited further to the MeSH® subheadings within "organ procurement" of "ethics", "legislation and jurisprudence", "methods", "organization and administration", "standards", or "utilization".

The abstracts and titles of the 50 resultant citations were reviewed with respect to the extent that they reflected 'utilitarian rationalist' or 'morally neutral' viewpoints in four domains.

The following concepts were defined as utilitarian rationalist.

- Organ donation occurring in the context of "organ shortage", including the terms "shortfall", "limited number", "insufficiency", "scarcity", "need", "demand", "availability", "supply", "long waiting lists", "die waiting" or "donor pool". Such terms were found in 26 out of 50 citations.
- Describing the discussion process with families as "asking for consent", "requesting donation", "obtaining consent", "refusal", "denied consent" or "conversion". Such terms were found in 18 out of 50 citations.
- Describing goals or outcomes of this encounter as "consent rate", "conversion rate", "efficiency of conversion", "increased donation rates" or "enhanced [procurement]", or "successful donation". Such terms were found in nine out of 50 citations.
- Descriptions of organ donation as "harvest", "procurement", "acquiring organs" or "organ recovery", or of donors as being "used or utilized as organ sources". Such terms were found in 23 out of 50 citations.

The following concepts were defined as morally neutral.

- Organ donation occurring in the context of "end-of-life care", "bereavement" or the "death of a relative". Such terms were found in five out of 50 citations.
- Describing the discussion process with families as "offering the option", "discussing organ donation" or "raising the issue of organ donation". Such terms were found in two out of 50 citations.

- Describing goals or outcomes of this encounter as "promoting good end-of-life decision-making", "meeting the needs of unfortunate families", "communicating sensitively and sympathetically" or "donor family support". Such terms were found in three out of 50 citations.
- Descriptions of organ donation as "donation", "organ removal" or "organ retrieval". Such terms were found in 19 out of 50 citations.

Of note, the MeSH® term "organ procurement" is itself defined in utilitarian terms: "The administrative procedures involved with *acquiring organs for transplantation* through various programs, systems, or organizations. It includes *obtaining consent* and arranging for transportation of donor organs, after tissue *harvesting*, to the hospital for processing and transplant."

Other searches were made of the Medline database, of the Cumulative Index to Nursing & Allied Health database, of the Allied and Complementary Medicine database and of the PsycInfo database for English-language articles generally pertaining to organ donation in the ICU (including, where relevant, transplantation, death and dying, and end-of-life care). Moral assumptions about organ donation, particularly about the encounter with the family at which organ donation is discussed, were sought. The dominant rational utilitarian view is herein illustrated by examples, and the minority moral neutrality view is presented and supported by personal experience.

Utilitarian rationalism

Morality, duty and obligation

Clinical results of organ transplantation are excellent for most recipients of transplant organs [4,5], and indeed transplantation has been described as a "social good" [6]. Does it follow, however, that organ donation is necessarily a social good? Kluge suggested that "every organ that is not retrieved represents not only a potential death or continued disability, but also an increased drain on society's healthcare resources" [7]. Is donation morally superior, as Etzioni recently suggested: "A communitarian approach to the problem of organ shortage entails changing the moral culture so that members of society will recognise that donating one's organs once they are no longer of use to the donor, is the moral (right) thing to do" [8]? Or is donation a moral duty, as Peters has argued: "Consenting to the taking of one's organs after death is a moral duty – the duty to consent – which derives from a more general moral duty – the duty to attempt an easy rescue of an endangered person" [9]?

The moral implication of such views is that to donate is, in some way, *better* than to not donate.

Various authors have more recently described donation as a social obligation: "Having had one's medical needs met over the course of one's life entails a *prima facie* obligation to

donate cadaveric organs in order to meet the medical needs of others, provided that it does not violate one's belief in the value of the body" [10] and "Rather than a 'gift of life', we should convey the idea of 'sharing a social right and obligation' ..." [11]. In a recent extreme position, Harris argued that "... the benefits from cadaver transplants are so great, and the harms done in going against the wishes of those who object so comparatively small, that we should remove altogether the habit of seeking the consent of either the deceased or relatives. This would be another example of a small but significant class of public goods, participation in which is mandatory" [12].

This growing 'communitarian' viewpoint stresses the concepts of social obligation and recipient entitlement.

Moral authority

It is commonly suggested, particularly by those who do not discuss organ donation with families, that the dead person's wishes have a greater moral authority than those of the survivors.

For example, an organ procurement organisation in the United States adopted a policy of acting on the documented wishes of individuals to donate, independent of family consent, and this decision has been described as "not only justified but morally required" [13]. Similar sentiments include those of Spital ("Mandated choice offers an alternative to obtaining consent from the family by returning control to the individual") [14] and those of Kluge ("Unfortunately, neither comes to grips with the real issue: Is it the potential donor who has the right to decide what shall happen to her/his body, or is it someone else? Does informed consent count, or doesn't it?") [7].

These views are reportedly in accord with the beliefs of the majority of transplant professionals, who favour "the wishes of the individual over the family in determining donor status" [15], and with the lamentations of a recent editorial in the *New England Journal of Medicine*: "Unfortunately, despite the validation of advance directives, donor cards, and other instruments of consent to donation, physicians and organ-procurement organizations still insist on consulting the families of potential donors and following their wishes" [16].

Language and the nature of the organ donation encounter

The discussion of organ donation with the family has usually been described as "asking for", "requesting", "seeking permission" or "obtaining consent" for organs or organ donation [17–19]. In this paradigm, a decision to donate is described as "consent", "permission" or "agreement", and the contrary decision is described as "refusal" [20–23] or "denial" [24–27].

The encounter is similarly described as "successful" if donation takes place [18,28,29], and the "consent rate" is

taken as the relevant measure of "effectiveness" or "performance" [17,30]. The encounter takes place in the context of a "shortage", "shortfall" or "inadequate supply" of organs for transplant [8,16,24]. Measures that may increase the "consent rate" are reported, including the use of "trained requestors" [3,31] and "support" from on-call volunteer "Mothers of Donors" [32]. Persuasion is explicitly recommended: "Specific steps can be taken by HCPs [Health Care Practitioners] and OPO [Organ Procurement Organization] staff to maximize the opportunity to persuade families to donate their relatives' organs" [33], and "Further approaches after an initial negative answer can be attempted, with appropriate arguments directed towards reversal of the refusal" [34]. As an example of the 'effectiveness' of such measures, Marmisa and Escalante reported an increase in "consent rate" from 59% at first "request" to 81% after "up to five additional requests" [35].

What is inadequate about utilitarian rationalism?

Utilitarian authors largely ignore the interpersonal reality of the situation in which organ donation occurs (namely, an encounter between a newly bereaved family and a health professional, at which donation is discussed), and focus instead on the benefits that accrue to recipients of transplant organs. This leads them to advocate practices and policies that 'should' increase the number of organs available for transplant (e.g. removing organs without the agreement of family members, presuming 'consent' and denying the moral or legal legitimacy of family wishes if these are not pro-donation or are contrary to those of the now-deceased).

Childress noted eloquently that "Organ transplantation is a very complex area, because the human body evokes various beliefs, symbols, sentiments, and emotions as well as various rituals and social practices. From a rationalistic standpoint, some policies to increase the supply of transplantable organs may appear to be quite defensible but then turn out to be ineffective and perhaps even counterproductive because of inadequate attention to these rich and complex features of human body parts. Excessively rationalistic policies neglect deep beliefs, symbols, sentiments, and emotions and the like, and that deficiency marks many actual and proposed policies" [36].

Most transplant surgeons will not remove organs for transplant without agreement from family members, out of concern for the adverse effects that such a practice might have on public support for organ donation. Organ donation may indeed be highly sensitive to adverse publicity [37,38]. Furthermore, even when organ removal is legally permitted under such circumstances, most organ procurement organisations do not perform it, most commonly citing concern for the effects of the practice on the donor family [39]. These concerns echo those of intensivists who recognise that organ donation is part of end-of-life care in the

ICU, which should be characterised by respect and compassion for the patient and family [3].

It has been argued that the level of community support for organ donation can be used to justify presumed consent legislation [40] or a more aggressive approach to the encounter with the family [41]. Indeed, although knowledge and support of organ donation varies widely in the community [42], there is substantial public support of organ donation, at least as measured by attitude surveys asking about 'willingness to donate'. More detailed analysis of the meaning of such a 'pro-donation' stance [43] has revealed a dialectically opposed position of "qualified support", related to brain death, commodification, disfigurement, fragmentation of the body and the role of the medical profession. Survey responses are context dependent, and support of organ donation becomes less as the context comes closer to the reality of the organ donation process. For example, although 86.6% of respondents in one survey were "in favour of donation", only 56.3% were very or somewhat likely to donate and only 64.1% were very or somewhat likely to agree to donation on behalf of a loved one [44]. These are figures closer to the 54% reported for family agreement to donation in the United States when this is discussed in reality in the ICU [45]. Even though 63% of a large sample of the Spanish population was favourable towards organ donation, only 24% agreed with a presumed consent law while 53% thought it was an abuse of authority [46].

The status or identity of the person making the 'donation' is a more fundamental point at issue. Organs are retrieved from the body of the now-dead person – in that strict biological sense, they are the donor. It is semantically and factually incorrect, however, to imply that the donor 'consented to donation'. After brain death the individual is no longer present to 'consent', although their 'previously expressed wishes in the event of their death' may have been documented. Furthermore, although these wishes may have been based on some understanding of the benefits of organ transplantation, they would not meet current standards for 'informed consent' in a personal healthcare context (see, for example, [47]). Specifically, these wishes may have been recorded as part of renewing a driver's license or passport, on registering with a general practitioner, on attendance at a pharmacy, to an automobile insurer or credit union, or via a website or by postal registration [48]. They would not have included full and explicit information about the procedures to be followed, and about the effects that such postmortem procedures might have upon others whose interests might be affected (e.g. surviving family members), or would not have allowed opportunity for such discussion, clarification and consultation as might arise.

The legal status of the body (at least in most Western jurisdictions) is unusual, neither being that of a living 'person' nor that of 'property' in which full possessory and proprietary

rights are vested [49]. Existing language does not adequately distinguish this 'other state of being' (neither person nor property), and the words commonly used to describe the nature of a 'previously expressed wish' after death (consent, permission, intent, authority) do not allow for this distinction. Rather, the words appear to imply 'persistence of personhood' after death (and thereby support a utilitarian perspective on organ donation).

It can be argued that the process of 'donation' does not involve the 'donor' at all after brain death and that the 'donation' is made by others. The emotional reality of this interpretation was certainly recognised in transplantation long ago [50]. It has been suggested [49] that assigning priority to the family's wishes could be necessitated by Article 8 of the European Convention on Human Rights [51], which requires respect for family life. The issue of 'rights' to decide the fate of body parts after death remains semantically and clinically problematic in organ donation practice. Although "... a non-existent person cannot truly be said to own something" [52], it might be argued that the will of that former person might still have binding power "not because of the rights of the non-existent person, but rather the implied promise by society to honour somebody's wishes, even after that person was deceased" [52]. However, the family of the now-deceased are the 'closest' part of 'society' to the deceased, but they may never have been consulted or may not have entered into any such promise, implied or explicit, or indeed in prior discussion may have explicitly refused to make such a promise.

Some legislative and regulatory attempts to resolve (or perhaps arbitrate) this issue have reflected a utilitarian viewpoint; for example, The Uniform Anatomical Gift Act: "Except for this last provision expressly permitting a person to object to organ donation, the 1987 Act's innovations all serve the purpose of encouraging organ donations by making them easier and by increasing awareness of the need for donors. It is hoped that the 1987 Act will serve to increase the number of organs available to those who need them for continued life" [53]. Similar utilitarian considerations – see, for example, "The potential costs to society of an inappropriate regulatory scheme are stark. It has been estimated for example that more than 1,100 people died whilst on the waiting list ..." [49] – may prevail in the United Kingdom following the Alder Hey affair [54], and perhaps in New Zealand after similar events [55], as similar Human Tissue Acts in these countries that govern organ donation are undergoing review.

The contrast between the interpersonal attributes of these procedures and those relating to (noncoronial) autopsy is striking. It might be thought distinctly strange to consider obtaining 'consent' or 'authorisation' from a person for an autopsy to be performed upon them at some unknown future time and mandating that such a decision would necessarily lead to an autopsy being performed, as an expression of the "primacy of autonomy of the individual", despite the

objections of surviving family members. Such an idea has some support in the current review of the UK Human Tissue Act 1961, but is strikingly at odds with the balance of sensitivities implied by the current clinical practice of explicit informed consent for an autopsy only being sought from family members after the patient's death (see, for example, [56–58]).

A morally neutral position

Moral neutrality allows the option of organ donation to be offered with confidence and compassion, and without apprehension or apology. This position accepts that organ donation is an intensive-care activity, within the realm of end-of-life care [3,59–62], and is separate from, not a subspecialty of, transplantation.

As intensivists are responsible for the care of dying patients and their families, we should be expected to be responsible for ensuring quality and integrity of organ donation practices in the ICU. These practices include humane and compassionate patient care, the avoidance of suffering, the maintenance of dignity and respect, and continued evident medical involvement. Our responsibilities also include caring for and about the family – ensuring that they have access to their loved one during the dying process, that they have consistent meticulous communication and that sensitive language is used with “evident compassion” [63]. Specific to organ donation, our responsibilities should include leadership – acknowledging that this is part of ‘our core business’, taking responsibility for it, studying it and writing about it, and being accountable for all aspects of the process – including the determination of brain death, identification of the possibility of organ donation, providing physiological support of the potential organ donor, ensuring that the family understand that brain death has occurred and, I contend, facilitating the discussion of organ donation with the family [60]. ‘Trained requestors’ do not share the relationship that has developed between the intensivist and the family, which is characterised by trust and mutual respect.

Framing this discussion as “offering the option of donation” frees us to act as ‘honest brokers’ – remaining focused on the integrity and the excellence of the process, neutral to the donation outcome and respecting the legitimacy of the family decision. The discussion might therefore begin (after evident understanding of the fact and meaning of brain death from the family) with a statement such as “There is one other matter that I wish to discuss with you and that is the option of organ donation. This is a situation where organ donation is possible.” We must have the necessary time and expertise (see, for example, [64]) to be able to discuss all relevant issues; including, for example, the previously expressed wishes of the now-deceased, prior discussions of these wishes with family members, feelings and beliefs of family members, the timing and nature of procedures involved in organ removal in the operating room, the opportunities for

viewing the body after organ removal, effects of organ removal on autopsy procedures or funeral plans and perhaps the organs that might be able to be transplanted and the probable consequences, as well as any other issues that the family need to discuss.

Intensivists often facilitate decision-making in other related contexts [65] (e.g. limiting or withdrawing intensive therapies) and could use these skills, without persuasion or coercion, towards the goal of facilitating an informed family decision about organ donation, based on a robust understanding of all the relevant issues. Such an approach should benefit families by ensuring that their needs are recognised, respected and sympathetically addressed, and by conveying the message that their decision, made under such circumstances, is respected and accepted. It should benefit all who work in the ICU by demonstrating that organ donation can be discussed with confidence, openness and compassion, and need not be contemplated with a sense of unease. There is a potential that such an understanding might reduce the number of occasions when organ donation is not discussed, out of apprehension or unease. It should benefit the transplant community and transplant recipients by ensuring that since organ donation has taken place in a manner free of coercion and manipulation, the subsequent transplantation activity is at a level that accurately reflects its societal support. There is a potential that, perhaps in systems that are strongly coercive, the number of organs available for transplant might decrease but, equally, there is the potential that such an approach may lead more families to agreeing to donate as a result of the absence of a sense of obligation. These matters require empiric investigation.

Conclusion

A rational utilitarian viewpoint of organ donation, based on the utility of organs to transplantation, does not encompass the moral dimensions of the issue in the ICU. A morally neutral position, where organ donation is seen as an option that intensivists should confidently offer to families of appropriate patients, more closely reflects the interpersonal reality of the situation. Such a process should find more harmonious accord with the compassionate culture and values of good end-of-life care in the ICU [66], and should more robustly reflect societal acceptability of organ donation (although it may or may not ‘produce more donors’).

Competing interests

None declared.

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