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Organ donation ethics

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Item Type	Article
Authors	Fisher, Michele Battle
Publisher	Online Journal of Health Ethics
Rights	With permission of the license/copyright holder
Download date	2026-11-14 21:48:34
Link to Item	http://hdl.handle.net/20.500.12424/176335

Organ Donation Ethics: Are Donors Autonomous within Collective Networks?

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Abstract

Can and will a person become an organ donor? Before such an altruistic act will occur, there is the ethic behind the action. There is an internalization of an ethic that the person agrees or disagrees with organ donation, no matter the variant. There is a large sense of agency and responsibility over the integrity of one's body. We do care what our "network" thinks about our personally held norms of living donation and sanctity of the body. I present the position that understanding of the norms of living organ donation requires an examination of the personal social "network" surrounding the potential donor. Networks rely on connection which may lead to deliberate consensus building (or a reason to conform in order to limit disharmony). But I argue, even when there is a supportive social environment supporting a particular bioethical value, there will be some level of network level engagement with others in this process (for better or for worse).

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You are not alone and I need your organ- the nature of social networks

Berlinger (2009) spoke eloquently of the dogged issue of the perpetuation in flawed reasoned (in) action within complex systems. But humans by nature are just that, complex and we must learn or not learn how to navigate in systems that were of our own doing. If complex systems defy description, I contend that we must look at the personal social network of the potential donors (Berlinger, 2010). Thank goodness that no man or woman is an island. Other people (and their valuable organs) are needed in consort with organ donation. The norms of living organ donation may be understood by mapping a network of close confidants (known as actors) that are linked by a particular circumstance. The central character or ego (ironically named so) is not alone with his or her thoughts. The ego is connected to others in a network whether large or small in size. The self-centeredness of an "ego's" ethical decision becomes complicated by its embeddedness in a network of concerned others. The ethic is now thrust into the public sphere.

We ontologically explain the health disparity of organ donation with statistics and modeling. This is only a part of the narrative, enumeration as foreign to the ego as the connectedness to the entire population of End Stage Renal Disease (ESRD) patients that only emotionally reach as far as those they know and care about. Each family is aware of the finiteness of opportunity cost for their loved one; a kidney transplanted to another without a donor in replacement lengthens the odds of a miracle. Most living donations come from biological related donors. This will be the network. Will "Uncle John's" kidney to "Niece Jane" serve to soothe the concerns of the collective personal network, the family? (Jones, 2009). You are facing your network and decision that is ultimately made. There is a layering of judgment of morality. An event that may begin in earnest as an autonomous act is no longer so. One must account for the heteronomy, or difference in values that may be wrought and perpetuated by the network.

Please agree with my values. We are family.

A question to ask might be the moral entropy brought out when the values of members of a social network differ. More likely than not, everyone will never agree. In addition, ethical values are transitory and have gradients of buy-in. "Potential" has its distinct silos in organ donation. As a potential donor, individuals fall into three categories:

1) A "potential" with viable organs to agree and then act as donor
2) A "potential" with viable organs to choose not to act now (which the hope that this could change over time) but not against the idea, or
3) A "potential" with viable organs that is unobtainable with negative ethics toward donation.

We continue to define donors as "potential" even if their bioethics position is contrary (Fox, 2010). 'It ain't over till it's over' (unless your body fails). Human agency and the ability to change one's mind give an ethical malleability makes changing ethical positions possible and clinicians a glimmer of hope for a successful convert.

But what does it take for an ethic of a potential donor embedded in a network with powerful contrary values work? As a hypothetical example, Ann has a quandary. Perhaps a discussion with her grandmother last week resonated and reaffirmed that the body is a temple that must stay intact from womb to tomb. Grandmother is praying for a healing for her ailing granddaughter. Ann supposes that this healing does not involve donation. She is told not to disrespect her elders. Does that include disagreement in ethics? It appears to be causing mounting trepidation for her. But her first cousin is languishing on dialysis and looking for a match. Ann wonders if she could be the one that is the match. At a family gathering, the issue of the cousin came up as complications from ESRD forced her absence for this first time. Ann asked over dinner if anyone is considering checking for donor compatibility. Some nodded as the statement dissipated while others left their intentions unknown by staying

silent. But what is understood in this exchange, the ethic of donation or the intentionality to donate. Or both? In a social network, which sentiment will prevail, the vocalization or the silence? This is nature of human negotiation. It is social and messy.

A collective change of "ethical" heart

Networks may cross based on purpose or be marked by isolation of some from the majority of actors. There is great hope and progress in public health that intervening with evidence based medical information will be associated with an appropriate and lasting change of behavior. I add that there must also on some level be a change of bioethical "heart" at play, as well. As social beings, negotiation of social agreement often requires personal engagement with people we trust. If an ethic develops at a larger level, how might success of a positive donation ethic be accomplished if consensus may be made as a collective of individuals that they know? Likewise, how much does one person hold in influencing the ethical beliefs of others around them if the overall moral position contradicts the larger system network level? These are questions that need to be posed in the years by bioethicists to come.

Organdonor.gov lists in its "Get Started" tips for declaring donation intentions the point to familiarize your family with your decision (U.S. Department of Health and Human Services, n.d.). This assumes that one's ethic aligns with the "decision" rendered to others or that there will be a "collective change of heart". As Fox (2010) notes that a less charged setting would be appropriate for discussing postmortem donation, what of the charged reality that there is a collective ethic that may be working against donation? I posit that network members by nature are emotionally invested. It would be best to approach this health discussion as it is- emotive and difficult to navigate in all circumstances. Living donations are more likely to come from family. This "talk" enters the process at delayed juncture. They may very well have been socially influenced by the very advocates that were asked to support during the big disclosure. Again, explore the nature of the networks.

There is much to be said about defying the overall collective ethic of one's social network when the act for donation actually occurs and becomes embodied in convalesce and a physical scar reminding of the removal of "Uncle John's kidney" (Jones, 2009). Unlike most illness discourses, there would not physical changes to the body that the network would have to grapple warranting medical intervention. Most chronic illness is a deal breaker in living donation. So what is left is a negotiation of a possible medical event that can place an otherwise healthy individual in possible harm's way (though risks are miniscule). The potential donor is asked to play a role as a giver of organs and live to tell the story that end with a happy ending for another (Battle-Fisher, 2009). Take Jones' (2010, p. 696) well grounded point of the continued attachment of the transplanted organ to the donor. I would expand this to the social network of the donor as well. The network is consistently reminded of the divergent decision and may be called to help the donor when they disagreed with the initial decision. There goes the extemporaneous harmony. Exit stage left.

The risk and rewards become that of the collective. Life no longer exists as an individual attribute but one that is negotiated with the needs and desires of the network in mind. The increased risk of chronic kidney disease and End Stage Renal Disease is outstretching the decreasing supply of viable kidneys available after each donation (assuming replacement that does not keep pace). As bioethicists, we may not be a part of the closest links to a patient's network before the need to (re)visit a personal position on living organ donation. We become players more conventionally if called in for clinical ethical consultation or as a reference to a well penned case study. This position does not decrease the relevance of understanding how these networks work beyond our inkwells.

Are bioethicists "weak" in the network?

Each network member's strength in influence is not created equal. In network theory, Granovetter (1973) posited in his well-known studies the strength of "weak" ties. This is a

hallmark in social network theory. Certainly bioethicists should be labeled as weak in the conventional sense. Bioethics has a vested interest on some level of the ethical declaration but because we are not competing for shared resources as a "strong" tie (e.g. we are not competing for the kidney) (Granovetter, 1973). Bioethics may need to acknowledge and perhaps embrace this less intimate bridging position that has been allowed within the network of patients. It can be much harder to become a maverick when surrounded by close strong ties that may resist opposing views. In this case, when many may covet that there be cohesion in a bioethical stance, strong ties may be to its detriment making departure from the overriding network norm more difficult to accomplish. For instance, living organ donation will most likely not be able to be hidden from view therefore it becomes a public experience that the person's network will share on some level. Weakness of a tie is a measure of probability of chances for access to the patient who needs to make the decision. Coming to terms with beliefs in mortality and morbidity does not occur exclusively within the heightened circumstances of a personal catastrophic illness.

Conclusion

But as time passes the physical body can only take so much wear and there will be a watershed "moment" when a loved one, such as Ann's cousin, needs an organ. The prevalence rates cruelly illuminate this possibility. We may discuss certain issues with the Thursday night bowling league and a radically different set of bioethical beliefs in Sunday school. But we hold a quiver of beliefs though they may only be selectively shared to select actors. There may be other links to the patient that may overshadow the effect of a bioethical position. But the nature of networks, allows on some level, that even more distant members in a network still have a chance as influences must be members of the network. You need to be in the network. In a directional network, givers and receivers reciprocate the negotiation of ethical resources. Perhaps by understanding the differing positions and nature of links that

members of a network may hold, bioethics may be able to better elucidate the nature of ethical deliberation as a living, changing entity. The most complex system is the one in which we have the most to lose. Then it is up to human agency, clinical knowledge and a network of gatekeepers as to an organ's fate.

Editorial Note: The opinions expressed by authors represent those of the authors and do not reflect the opinions of the editorial staff of The Online Journal of Health Ethics.

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