

When You Can't Trust What You Don't Know: organ and tissue donation, public trust, the voice of dissent and informed consent

HARMONY PEACH

Department of Argumentation Studies, University of Windsor, CA
peachh@uwindsor.ca

This paper examines the apparently good reasons for becoming an organ and tissue donor (OTD) in "opt-in" public recruitment and registration discourse (PRRD). It explores how public trust is employed to encourage assent to the notion that donating is the right thing to do, and it considers whether expert ethical concerns for OTDs omitted from PRRD may offer good reason for public dissent. It also examines how persuasion in PRRD contravenes the tenets of informed consent.

KEYWORDS: organ and tissue donation, public trust, public recruitment and registration discourse, expert ethical debates, dissent, informed consent, presumed consent

1. INTRODUCTION

Good reasons and rational justification for becoming an Organ and Tissue Donor (OTD) are replete in the dominant Public Recruitment and Registration Discourse (PRRD) in so called "opt-in" jurisdictions where the public must actively consent to donation. Government officials, medical and legal professionals, *experts* in the field, contend with, and rely on, public trust to adhere that organ and tissue donation is "the right thing to do." On the one hand, the public's acceptance of the trustworthiness of experts is used to assuage, and even to discount, public dissent to advance a claim that the public *should* assent to organ and tissue donation. This also demonstrates that on the other, the public may not wholly trust that it should and therefore requires expert reassurance. Hence, policy-sanctioned public service announcements, which prompt people to trust the official "ask" for their consent to donate, employ a narrative discourse consisting of "good" reasons for donation which focuses on saving or improving lives. Donation helps people to walk and see again; it restores burn victims. Donors are

framed as “heroes” who bestow “gifts of life.” However, there is also an Expert to Expert Debate (EED) or discourse of dissent within the medical literature about potential risks to organ and tissue donors which seems to either be omitted from or presented as resolved in the PRRD. Debate continues about definitions of death, waiting periods for organ procurement post-declaration of death, and even whether there may be the potential for latent feeling and/or resuscitation. Given that the public is predisposed to view expert discourse as trustworthy, I suggest this EED may then afford the public good reasons for its own dissent, yet it is being discouraged from doing so through the misuse of public trust. Moreover, I argue the EED in the medical dissent discourse suggests the aforementioned “good” reasons for why people *should* or *ought* to donate amount to rhetorical device and hence persuasion in the OTD recruitment and registration discourse which contravenes the avowed tenets of informed consent. The medical voice of dissent suggests serious ethical blind spots for OTDs. Yet, the public is asked, based on the expert discourse disclosed to it, to accept the narrative that leads people to conclude they “do not need their organs and tissues after death” seeming to suggest that OTD “death” is beyond reproach or is definitive in both its medical context and meaning. In this paper I unravel the web woven out of public trust as it relates to the various levels of discourse operational in the context of organ and tissue donation. The relationship between public trust and expert discourse in this field demonstrates that a public grooming process that organ and tissue donation is the “right thing to do” is in contrast to a lack of medical information regarding the procedures involved in the OTD process, which violates trust in informed consent.

2. INTRODUCING TRUST

Apparently good reasons and rational justification are replete in Public Recruitment and Registration Discourse (PRRD) in opt-in (actively expressed consent) and opt-out (presumed consent) jurisdictions. Here, I focus generally on the North American context and explain why the Canadian context is particularly relevant. I suggest the public may have reason for dissent from organ and tissue donation when the PRRD is tested against informed consent tenets in opt-in jurisdictions, particularly when we consider that much of the dissent in the Expert to Expert Debate (EED) is either omitted or presented as resolved in the PRRD. The Journal of Transplantation notes that organ and tissue donation

“constitutes a complex ethical and value laden field of interdisciplinary interventions. It is a surgical and medical

field that requires the highest scientific standards, but likewise one, where ethics, values, and personal beliefs play an immense role. Not surprisingly, then, extensive research has been done on attitudes to [OTD]...often with the explicit aim of investigating whether they “have the knowledge needed to maximize organ donation rates” or “to inform strategies to improve organ donation rates” (Hvidt et. al., 2016, para. 3).

Indeed, maximizing donation rates is often the impetus for much research within the field of organ and tissue donation (OTD). At the crux of the matter for maximization is public trust in the OTD process and the experts within it. In order to unravel the web woven out of public trust in the OTD process, the place to begin is to first discuss the general characteristics of trust, before offering an account of public trust. I can then address (only) some of the PRRD and EED against informed consent tenets in organ and tissue donation in order to pinpoint how some of the arguments for donation are misusing public trust and contravening informed consent.

Generally, researchers are still debating the characteristics of trust, but they have come to some agreement about its key features which bioethicist David Resnik (2010) has summarized nicely. First, trust is a relationship between or among people. It can be explicit (like contractual promises) or implicit (like following traffic rules). It can be concrete (trusting a doctor) or abstract (trusting the medical profession). Trust’s main purpose is to “facilitate cooperative social interactions” (Resnik, 2010, para. 6). It involves risk-taking or a leap of faith. Essentially, you trust in what you do not know for certain. It has a relationship to trustworthiness. The trustor requires evidence that the trustee has qualities which include competence, experience, sound judgment, reliability, good will or benevolence which merit giving them their trust. This is what separates trust from faith which involves belief without evidence. “Trustworthiness can be earned, enhanced, or lost (Baier, 1986, Blomqvist, 1997)” (Resnik, 2010, para. 7). Finally, “trust can generate ethical and legal duties (Baier 1986). The entrusted person has an obligation to do what is expected of [them] in the relationship” (Resnik, 2010, para. 8). Informed consent, for instance, is a legal and ethical obligation and when trust has these obligations it is a form of promise-keeping (Resnik, 2010). The public relies on a hierarchy of medical, legal and policy experts, ordained by governments, for its understanding of, beliefs about, and interaction with the various levels of OTD, particularly for affirming informed consent. Canadian Philosopher Trudy Govier notes in her book *Social Trust and Human Communities*, that we cannot help but to “depend on each other for knowledge and evidence” especially when we consider specialized knowledge and our ability to verify it or not for ourselves through direct

experience (Govier, 1997, p.53). On most topics, most people are not, in fact, experts and therefore “depend on experts for many of their beliefs about these topics” (Govier, 1997, p. 54). And while this does not preclude us from being able to fact check some claims made by others, it is “only by relying on the claims and reports of still other people” that we do so (Govier, p. 54). So, trusting experts, even when their opinions differ, is a necessary part of our decision making. Thus, hearing from those experts who offer varying opinions is also necessary, particularly when informed consent is a standard which must be met when we make our decisions.

3. PUBLIC TRUST

We often use the term *public trust*, but there really is no concise definition of public trust. Again, Bioethicist David Resnik has attempted to tease apart what, exactly, *public* means in public trust, particularly as it relates to scientific discourse. He is motivated by helping various experts make better arguments for public trust in science. He says “[t]he idea that it is important to promote public trust in scientific research has been used by so many different authors in so many different contexts that it is in danger of becoming a platitude. Even worse, overuse of this concept may lead to ambiguity” (Resnik, 2010). In a general sense, what we mean when we say “the public” is actually *society as a whole* and he argues that it makes sense that a society *generally* trusts science to be careful with public resources, and to provide knowledge and expertise that can inform public policy. However, “drawing specific ethical and policy implications from this idea can be problematic because” essentially, society is highly diverse and made up of many publics that may have divergent expectations of science (Resnik, 2010, para. 23) which means there needs to be nuance in how science, and in this case organ and tissue donation PRRD, communicates with different publics which requires trustworthiness.

In their consideration of moving trust towards trustworthiness Aiken, Cunningham-Burley & Pagliari also recognize that “[g]iven the central role of scientific knowledge within society, publics have little choice but to trust in science. But [they clarify] this trust remains conditional and does not mean that [publics] will inevitably have confidence in...scientists or scientific institutions” (Aiken, Cunningham-Burley & Pagliari, 2016, para. 14). Moreover, they say a binary of either the public trusts or distrusts is not nuanced enough to capture the complexity of the trust relationship the public has with science. Instead, the way to advance public trust is not to focus on creating an automatic trust response, but to have scientific institutions and their experts consciously share the trust responsibility. They argue “[t]here is a need

for more symmetrical and reflexive considerations of what it means for publics to trust science, and equally of what it means for science to be trustworthy” (Aiken, Cunningham-Burley & Pagliari, 2016, para. 17) and I agree. Organ and tissue donation sits somewhere between the general sense of public trust as ‘society as a whole’ because the goals of those seeking public trust are to maximize donor rates which involves trust from everyone, and ‘individual publics’ because there are cases that differ across context and culture like religious practices and recruitment differences by region. For instance, in the United States the PRRD often speaks to tissue donations helping military veterans to walk again, but this is less prevalent in the Canadian recruitment context. So, OTD PRRD often seeks to establish, maintain or build public trust in a general sense, and in a more targeted or specifically contextual sense. Prospective donors or their proxy decision makers, if they choose donation (and are not themselves experts in the field), then trust what they do not know directly for themselves because they are relying on the PRRD presented by experts which shapes their beliefs about consenting to donation.

There are many reasons why people do not agree to donation, and some of those reasons are motivated by mistrust. I will handle two such reasons here: 1) there are concerns about donors not truly being dead, and 2) whether they will receive adequate healthcare if they register consent. These can be characterized as necessary public dissent as the EED will later show. Meanwhile, the PRRD not only presents “facts” about OTD, but reasons for consenting to donation in order to increase public trust for the express purpose of increasing donation and quieting dissent. This nexus is where I argue the discrepancy exists between the PRRD in opt-in jurisdictions and informed consent tenets, and where what may be necessary public dissent is being dismissed as a need for more education while either omitting or downplaying similar dissent in the EED.

3. PUBLIC TRUST

The general tenets of informed consent are similar across jurisdictions, particularly in North America in both healthcare and medical research and are a necessary standard which must be met in order for people to opt-in to donation. Distilled, in order for informed consent to be affirmed, it must have been given freely and voluntarily, free of fraud, misrepresentation, coercion or manipulation and have involved a reasonable disclosure of all the facts needed for a reasonable person to make a choice that demonstrates risk and benefit assessment and that offers a dialogue for any needed clarification (Canadian Medical Association, 2014; American Medical Association, 2019).

In the Canadian context, The Canadian Medical Association states “[t]he purpose for providing the opportunity to choose to donate organs or tissues may be to procure organs or tissues for transplant. [But] [s]uccess in achieving this outcome should not be construed as a criterion for measuring the quality of the process of free and informed decision making. *The quality of this process depends on whether the choice is adequately informed and voluntary and not on whether the outcome is a decision to donate*” (Canadian Medical Association, 2014, p. 2, emphasis added). Therefore,

[i]n order for the choice to donate organs or tissues to be duly informed, prospective donors or proxies should be provided with meaningful, understandable information pertinent to the choice. [Most relevant for the purposes here, this] includes information about... the benefits and *risks* of donation... procedures concerning the determination of death... measures that may be required to preserve organ function until death is determined and surgical procurement can occur... [and] what will happen to the body once death has been declared (Canadian Medical Association, 2014, p. 2-3, *emphasis added*).

Essentially, people need to make the choice freely, voluntarily, and be given information about the donor process that includes the *benefits and risks of donation*; all “requiring the exchange and understanding of information and absence of coercion” (Canadian Medical Association, 2014, p. 2), fraud and misrepresentation (Health Care Consent Act, 1996).

In ‘*opt-in*’ jurisdictions, people must actively provide their explicitly *expressed consent* to donate which **requires** *informed consent*, and trust is used in recruitment and registration. In ‘*opt-out*’ jurisdictions *presumed consent* means people must explicitly withdraw their consent for donation and trust is used in retention. In both cases, the family can still hold the final say over donation, even by overriding registered consent so, trust is operational here too. However, a more recent practice in opt-out countries is that organs will be procured from eligible donors even if the family cannot be reached for consultation. The World Health Organization (2015) suggests moving towards a presumed consent model globally because there is evidence it yields substantially more donations. However, the British Medical Association has reported that a taskforce review shows not all opt-out jurisdictions have high rates of donation. It does not overtly state this is because of a lack of public trust, but it did advise that “improvements in... education, including public awareness campaigns” would significantly increase donation. These solutions hinge on high public trust (Prabhu, 2018, para. 6). The nuances between opt-in and opt-out are especially topical

in the Canadian context where OTD is currently opt-in, and handled provincially. However, the province of Nova Scotia has most recently decided to implement the opt-out consent model come 2020 while the rest of Canada, at this point, will remain opt-in. As this consent softening in one province may lead to justification for others to follow suit, teasing apart these complex relationships is necessary, especially when considered against informed consent in the opt-in model.

4. ARGUMENTS IN THE PRRD

Because the need for organs and tissues outweighs the available supply, the arguments presented in PRRD spend much effort offering apparently good reasons for becoming an OTD with the explicitly stated goal, not of informing consent, but of maximizing (or at least improving) donation rates. Most of these good reasons, however, are based on altruism which uses scientific expert discourse as evidence for its justification. This altruistic angle has a recognizable rationale that transcends geography across opt-in jurisdictions and relies generally on enthymeme for its effect which is ultimately meant to simultaneously encourage active consent registration, often through emotion, while discouraging public dissent. Essentially, both the stated and unstated are crafted to persuade the public to arrive at a decision that OTD is “the right thing to do” or what people should or ought to do. For instance, the PRRD features versions of providing people with the “opportunity” to “save or improve lives”; the “gifts” of solid organs allow the dead to “live on” through their “donations”; and “gifts” of tissue “help people to walk or see again or help to restore burn victims” or “improve lives.” Such narratives as “you can’t take your organs and tissues with you when you die so why not give them to someone who needs them and save a life?” are ubiquitous. Donors are regularly framed as “heroes” and PRRD often suggests that people “ought” to or “should” or “be responsible” or “kind” and “do the right thing” and register their consent to donation. Moreover, it has become a ubiquitous argument to assert that public dissent amounts to “barriers” of ignorance: a need for addressing questions purely for clarification and education, and a public belief in myths which need debunking so people will “make the right choice” to donate. Thus, the PRRD generally offers a list of “facts” which are meant to assuage “fears”, “answer frequently asked questions” and ultimately, to argue that the information presented by the PRRD about the practice of OTD is trustworthy, so people *should* choose to consent. Essentially the PRRD provides people with reasons specifically towards one choice-consent. If they do not choose consent, enthymematically, they are “making the wrong choice” or need better education so they can make the right choice or are selfish, or not heroes or kind, which I suggest is a

coercive framing of the discourse which poses serious concerns about just how much freely decided and informed “choice” is involved in the consent process. Deliberately peppered enthymeme in the framing of PRRD leaves the prospective donor expected to draw the conclusion that they will not be responsible or kind, or heroic if they choose the wrong option.

Some specific examples that are not at all unique include one from California’s online registration and recruitment website www.donatelifecalifornia.org where its “vision is that one day all Californians will embrace organ, eye and tissue donation as their personal responsibility” (Learn More About Donate California, 2019, para. 2). Unstated, is that those not donating are shirking a personal responsibility. In New York, the www.donatelife.ny.gov website says “[y]our kindness could save eight lives through organ donation, restore sight with cornea donations and improve 75 more lives with tissue” (Register to Become an Organ and Tissue Donor Today, n.d., para. 2). Unstated is that people who do not donate are unkind and do not want to save lives or help people see or improve the lives of others. In Ontario, Canada the registration and recruitment website www.beadonor.ca offers “[r]egistering to be a donor makes you a hero” (www.beadonor.ca More Ways to Register, 2017, para. 1) and that “[b]y registering, you are essentially making a decision to help save lives after death through organ and tissue donation” (www.beadonor.ca About Donation: Donation Process, 2017, para. 2). Here what is missing is that people will be villains or the opposite of heroes; by not registering they are essentially making a decision to end lives. Even the various names of donor registration and recruitment institutions are often directives like “be a donor” and “donate life” which also has subtle negative implications for free choice in informed consent.

5. ARGUMENTS IN THE EED

Further confounding the ethical implications for informed consent are the arguments occurring in the EED which also feature dissent, but are either omitted or presented as resolved in the PRRD. The guiding ethical principle in declaring death in OTD is the Dead Donor Rule (DDR) which is a “deontic constraint that categorically prohibits causing death by organ removal” (Nair-Collins & Green, 2014, para. 1). So, a declaration of death *must* be made before donation. There are two ways a person can die for OTD though not all are accepted definitions everywhere. The first is death by neurological criteria or “brain death”. Following no response to a series of neurological tests by two separate doctors, a person is determined to have no brain function, and will remain on life support for the purposes of donation. The second definition is Donation

after Circulatory Death or DCD which occurs when a person is removed from life support (and/or has wishes not to be resuscitated if they code while on life support). It is characterized by the irreversible cessation of cardiac and respiratory functions... [However] the brain is still capable [of] sustaining consciousness, integrative and vital functions" which is why there is a waiting period following DCD before organ retrieval. (Canadian Medical Association, 2014, p. 4-5).

Despite its generally well-regarded rigour, some deeply respected experts in the medical community (Verheijde, Rady, & McGregor, 2009) still question the efficacy of the brain death test which amounts to EED dissent. Generally, the brain death EED points to patients who meet all the criteria for brain death but do not in fact have "irreversible cessation of all functions of the entire brain," because some of the brain stem's homeostatic functions remain, such as temperature control and water and electrolyte balance, and some patients enter puberty or continue to carry pregnancies to term. To counter, others have argued that not all the functions of the brain need to be lost for a patient to be dead, only those that are critical to maintaining integration of the body functions, and that loss of these will inevitably lead over hours or days to cardiac arrest, even with continuing intensive life-support. Yet occasionally the bodies of some patients who meet all the criteria for brain death can survive for many years with all their bodily functions intact except for consciousness and brain stem reflexes" (Sade, 2011, p. 146). There is also a small contingent of the EED that questions whether donors in this state have some potential for pain or some latent, untestable awareness (Verheijde, Rady, & McGregor, 2009). EED dealing with circulatory death hovers on the practice itself and waiting periods which are in place to ensure enough time has passed for the body's death process to terminate, but not so long as to lose viable organs. As little as 75 seconds has been waited in Denver, Colorado and as long as 20 minutes is the standardized wait in France (Aita, 2000; Dead Enough, 2014). In Canada the standard is five minutes, but some hospitals wait 10 and there are variations on whether institutions accept DCD at all. (Dead Enough, 2014, para. 13-14).

EED also questions whether what is currently transpiring in OTD violates the Dead Donor Rule and therefore whether it should be abolished altogether (Rodriguez-Arias, Smith & Lazar, 2011). Given that live organs are procured from dead donors (according to the widely accepted medical and legal policies and practices), one side of the debate argues there will always be problems associated with the practice. Some, like Dubois (2011), insist even without the DDR, many people would still want a ruling of death before organ removal as not having one would create fears among donors and physicians. Others say the DDR death ruling allows for the public belief that donors cannot be

harmed during procurement as dead people cannot be aware of or feel pain. Here, dissent in the EED questions not at which point death occurs, as mandated by the DDR, but instead they want to debate when it might be acceptable to procure organs from dying, but not dead, patients which they argue is more akin to what is actually transpiring currently despite the DDR standard (Rodriguez-Arias, Smith & Lazar, 2011). I have not been able to find evidence of disclosure of this EED in the PRRD. I have found extensive discourse that assures people they will be “dead” when organs and tissues are procured which omits the dissent aspect in the EED from the public’s risk assessment necessary for informed consent. I have also found extensive evidence that employs the prospective donor’s supposedly non-debatable “death” as a kind of guilt mechanism which is meant to quash its dissent. It is because of the above dissent in the EED that the public may indeed have justification for its own dissent from OTD. If we must on some level trust the experts, then their dissent matters to informed consent as much as their arguments for OTD.

CONCLUSION

I have only been able to scratch the surface here in order to offer some of the concerns related to public trust in OTD with regard to discrepancies in PRRD and EED as compared to the tenets of informed consent. My purpose here was not to evaluate arguments, but to begin to tease apart how trust, and specifically “public trust”, are being deployed in the practice of recruitment, and to show how and where it may be being used to increase donation rates while not wholly enforcing the tenets of informed consent. As I mentioned at the outset, OTD is complex, and public trust is just one of the many moving parts which animate the various concerns within the practice. The purpose of this work has been to begin to sketch an account of how public trust is at work in OTD, and whether the ways in which it is being utilized is discouraging what may be necessary public dissent within the OTD practice.

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