Organ Donation: Autonomy, Presumed Consent, and Mandated Choice

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Abstract

Every year the demand for organs to be used for transplantation increases. With the progression of sophisticated technology, the ability to transplant these organs has never been easier; however, there are still an insufficient number of organ donors. In this paper, I analyze the idea of autonomy as presented by Degrazia, Mappes, and Brand-Ballard in their book, Biomedical Ethics, and explore the role it plays in ethical considerations as it pertains to organ donation. I then analyze the findings of James Stacey Taylor in his article, *Personal Autonomy, Posthumous Harm, and Presumed Consent Policies for Organ Procurement.* Lastly, I incorporate an article from The Journal of the Medical Association, *Strategies for Cadaveric Organ Procurement.* I argue that neither presumed consent nor presumed refusal preserve autonomy and that mandated choice, as defined and articulated in the JAMA article, is a far more ethically viable solution to the growing dilemma of organ procurement.

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The need for organ donors is growing at an ever tremendous rate. Historically, there has always been a broad chasm between the number of organs needed and the number of organs donated. There has been much effort exerted to persuade people to become organ donors and to participate in the battle to help humanity. The development of sophisticated technology has resulted in our ability to save more lives than ever before through organ transplantation; however, if organs are not available for donation, it makes little difference if the technology needed to transplant them exists or not. The pressing question that ethicists and physicians find themselves confronting is: How can more organs be procured for transplantation? How can we shrink the gap between the number of organs needed and the number of organs donated? Many ethical and moral considerations get raised through the exploration of these questions, considerations that must be addressed in order to arrive at a compelling answer. Autonomy, presumed consent, presumed refusal, and mandated choice are but a few of the options to enact a shrinkage to the gap of supply and demand. Autonomy is what must be preserved in any legislation concerning organ donation, but how it is defined and viewed will alter the variations of presumed consent, refused consent, and mandatory choice. I will argue that mandated choice is the best alternative to ensure the proper treatment of a person's autonomy while still procuring ample organs to shrink the ever-growing supply and demand gap of organ donors and organ recipients.

Autonomy is a multi-faceted concept, but it is one that must be adequately defined and understood in practical situations to begin a discussion of organ donation. Simply speaking,

"Autonomy is typically defined as self-governance or self-determination." (Degrazia, Mappes, & Brand-Ballard, 2011, p. 41)[1] This definition is broad and rather vague; however, it is clearer when thinking of autonomy to consider, "Individuals are said to act autonomously when they, and not others, make the decisions that affect their lives and act on the basis of these decisions." (p.41) Now, it must be understood that no individual can ever make a truly autonomous decision in the strict definition of autonomy. To make a completely autonomous decision would require that the individual have access to all of the pertinent facts prior to making the decision, and since it is inconceivable for the individual to have access to all of the facts, it can be said that no individual can ever truly make an autonomous decision. This being said, it is best to consider autonomy in terms of degrees. On some occasions, the individual will have more access to the facts concerning his decision than on other occasions. In the former case it can be said that the individual is making a more autonomous decision and in the latter case it can be said he is making a less autonomous decision.

For an individual to make any autonomous decisions, he must have intentionality, understanding, freedom from external constraints, and freedom from internal constraints. "To perform an action autonomously, one must, as a first condition, intentionally perform that action." (p. 41) In other words, the individual must form the intention and then volitionally act in the specific manner in which to manifest that intention into an action. Intention must precede the action in order for the action performed to be considered autonomous. Without intentionality

[1] David DeGrazia is a professor of philosophy at George Washington University where he has taught since 1989. He has published several works in the area of ethics, primarily in bioethics and animal ethics.
Thomas Mappes is a professor emeritus of philosophy at Frostburg State University, where he taught from 1973 to 2008. He has published several works in the area of ethics, and has works appearing in *American Philosophical Quarterly* and *Kennedy Institute of Ethics Journal*.
Jeffrey Brand-Ballard is an associate professor of philosophy at George Washington University. He has several publications appearing in journals such as *Ethics, Utilatas, Legal Theory,* and *Kennedy Institute of Ethics.*

on the individual's part, it cannot be said that he performed an autonomous decision because he did not formulate an intention.

Understanding is impossible to completely achieve as mere humans, so it serves better to break it down into matters of degree. Arguably, an individual cannot ever *precisely* know all of the information to make a decision or the ramifications that decision will have on the world around them. (p. 42) To better comprehend the necessary degree of understanding to make an autonomous decision, it can be said that the individual must possess a *sufficient* degree of understanding. Again, the word sufficient in the context above is dubiously subjective, and best conceived as a degree of scale. This also gives rise to the notion that autonomy is best characterized on a degree of scale.

External and internal constraints can also be best thought of in terms of degrees. "External constraints may be understood as including physical barriers deliberately imposed by other individuals and different forms of coercion." (p. 43) An example of a physical constraint would be the barbed wire, locked doors, and guards of a prison. Conversely, internal constraints can be anything internal to the individual that inhibits him from making an autonomous decision. "Intense fears, acute pain, persistent discomfort, and strong emotions such as rage and grief sometimes influence us to make choices that represent departures from our stable values and usual priorities…" (p. 43)

It is a controversial debate about whether autonomy persists after death and if it does to what degree. "It is often held that persons can be harmed by events that occur after their deaths if these events thwart their important desires or interests." (Taylor, 2006, p. 392)[2] Practically, we see this lived out. We do not advise speaking ill of the deceased out of respect for his dignity,

[2] James Stacey Taylor, as cited here in the *Public Affairs Quarterly,* argues that the "fewer mistakes" arguments are irrelevant to the debate of the ethical status of policies of presumed consent. He proceeds, in this article, to argue that there is no reason to believe that the posthumous thwarting of a person's wishes would harm them.

and, aside from legal ramifications, we stringently follow the directions of his will, or carry out the wishes he expressed while living even after he has passed away. Conversely, it can also be argued that since the dead have no desires, cannot form intentions, and lack understanding, they cannot be afforded autonomy and, thus, one can only respect the autonomy of the living. It must be understood that there is a distinction between disrespecting and violating an individual's autonomy. Two hypothetical examples can be explicated to illustrate these differences. In the first, a person might forcibly prevent another from getting into their car and driving to the store. The first person prevents the second person, because he knows the car has a gas leak and could explode if started. In this case, it could be said that the first person is violating the autonomy of the second by becoming an external constraint; however, it would be ludicrous to say he is disrespecting the autonomy of the second individual. Consider now the second example. Suppose an individual stands to gain a great deal of wealth when his mother dies. Suppose further that he is more than capable and willing to kill his mother to gain the wealth, but circumstances are such that he is never granted the opportunity. In this case, it can be said that the son absolutely disrespected his mother's autonomy, but it cannot be said that he violated her autonomy. The difficulty in distinguishing between disrespect and violation is defining what exactly is meant when it is said that an individual's autonomy has been "violated." (p. 390)

There are three ways to violate a person's autonomy. The first is by "inflicting brain damage upon her so that her ability to direct her own life in accordance with her desires and values is now impaired." (p. 390) Obviously, by depriving the individual of her mental capacity to form desires and intentions and to purposefully act upon those desires, her autonomy has been encroached on and violated. Secondly, "one might violate the autonomy of another by preventing him from using his autonomy to pursue his goals…" (p. 390) This would be true in

the case of a prisoner being held hostage. The external constraint placed upon the prisoner would render him incapable of action to bring his desires and goals to fruition. Thirdly, "one might violate the autonomy of another by usurping control over his actions, whether covertly or overtly." (p. 390) An example of this type of violation would be lying or deceiving another person, which would instill in them a false perception of reality and they would base their decision on that false sense of reality, thus resulting in a less autonomous decision. It is the concern for individuals' autonomy that drives much of the debate of between presumed consent and presumed refusal.

The current system of the United States as well as most of Europe for organ procurement is presumed refusal, which is also known as the "opt-in" system. In this system a person's organs cannot and, "will not be removed from her postmortem body unless she has explicitly consented to this being done." (p. 383) Under this system, citizens must "opt-in" to become organ donors by registering to become donors. Consequently, this method of procurement does not produce very many organs. This is true for a variety of reasons, which is why many are suggesting the United States should adopt a new system of presumed consent.

Diametrically opposed to presumed refusal, "under presumed consent it is presumed that persons would prefer to donate their organs for transplantation after their death." (p. 383) Presumed consent is also referred to as the "opt-out" system because individuals would have the option of opting out of the system and not donating their organs. On a moral level, the debate between presumed refusal and presumed consent seeks to achieve the fundamental goal of organ donation. The goal is to show that their respective systems of organ procurement are morally and economically superior to the other. Proponents of presumed consent use the argument of "fewer mistakes" to motivate their claim. (p. 383)

The proponents of presumed consent argue that acting on the presumption that people would desire to donate their organs for transplantation after death better respects most individual's autonomy rather than the presumption underlying the current presumed refusal system, namely that individuals would prefer not to donate their organs. Numerous studies and surveys have been conducted that suggest about, "…70 percent of Americans would be willing to have their organs removed postmortem for transplantation if they were suitable for this..." (p. 383) Contrast this with the 30 percent of people who would not choose to have their organs donated. It seems that presumed consent would be better suited to respecting people's desires than presumed refusal. Cohen[3], a biomedical researcher in support of a presumed consent policy, argues that this is the case, "…because very few people adequately indicate that they wish to donate their organs postmortem, and so their ante mortem wish to do so is not considered. What Cohen wishes to argue is utilitarian in nature, maximize the good for the most people possible.

However, opponents of presumed consent argue that, "presumed consent is ethically unacceptable since it is likely to violate people's ante mortem wishes concerning the postmortem disposal of their bodies." (p. 383) If presumed consent was adopted and individuals who did not wish to donate their organs, but failed to register their objections, their organs would, if suitable, be removed and transplanted, thus thwarting their wishes and violating their autonomy. Both camps wish to establish a singular claim: "that the method of organ retrieval they morally favor would lead to the fewest number of mistakes in the postmortem retrieval of organs. Hence, the "fewer mistakes" argument. This specific formulation is known as the *quantitative* fewer mistakes argument. Fewer people do not wish to donate their organs than those who do and the ones who do wish to donate are less likely to explicitly state or "opt-in" to the current system,

[3] C. Cohen is cited here by James Stacey Taylor. Cohen has many published works in the area of ethics, specifically bioethics. In the article by Taylor, Cohen argues that presumed ethical consent is permissible and quantitatively superior to presumed refusal – leading to fewer mistakes or violations of individuals' autonomy.

usually due to the presumption that the failure to do so would unlikely be significant to the individual. It is more likely that those who do not wish to donate their organs would be more copious due to "moral, prudential, or religious reasons" (p. 384) to explicitly state or "opt-out" of the presumed consent system. If this were the argument in its entirety, it would seem the proponents of presumed consent would have a better argument, since the vast majority of people wish to be donors, but are not registered and the system would save a great deal more lives.

The result though is that the "fewer mistakes" argument rests upon an implicit assumption that opponents of presumed consent do not accept: that mistaken removals and mistaken non-removals are morally equivalent. (p. 383) Opponents claim, that is not the case. They argue that mistaken removals are morally worse than mistaken non-removals. Therefore, they argue, while it may be true that there would be fewer mistaken removals under the presumed consent system, those mistaken removals would wield far more moral weight as compared to the mistaken non-removals. Incidentally, while it may be true there would be far fewer cases, the cases would be vastly more severe. This then distinguishes the second portion of the "fewer mistakes" argument, the *qualitative* portion. The qualitative argument, "rests on the claim that the *type* of desires that are thwarted by mistaken removals of organs are qualitatively different from those that are thwarted by mistaken non-removals." (p. 384)

Considering both the quantitative and qualitative components of the "fewer mistakes" argument and juxtaposing it with the three ways autonomy can be violated, it remains clear that defenders of the autonomy-based "fewer mistakes" claim is ungrounded. Close inspection reveals that neither the quantitative nor qualitative arguments meet any of the three requirements for violating autonomy. Thus, it can be stated, that "…the number of mistaken removals and the number of mistaken non-removals that are made would be irrelevant to the question of whether

or not the autonomy of the persons whose postmortem bodies are in question would be violated." (p. 390-391)

Underlying the prevailing thought of many proponents of presumed consent is the communitarian ethic. "The communitarian view holds that individuals have a moral duty to help others when the cost to the individual of helping is very low." (JAMA, 1994, p. 811) Obviously, in the case of a deceased person the cost of donating an organ to potentially save a life is very low. However, "although we have a moral duty not to harm another, it is not so clear that anyone has a duty to help others when the help entails the postmortem surrender of a part of the body." (p. 812) Therefore, we are all entitled to a *negative* right, the right to not be harmed and the duty to not harm, but it is doubtful if we are obligated to a *positive* right, or a right to be helped and a duty to help. While it is true that some states have adopted Good Samaritan Laws, traditionally the law has viewed the duty to help others as a moral duty left up to the conscience of each individual. While the hope is that most people would help others, it should not be made illegal to refrain from helping others. The underlying principle of the communitarian ethic is a morally good one; however, it is an entirely distinct issue to legally require someone to help others.

What both proponents and opponents of presumed consent often overlook is the individual's choice prior to death. Mandated choice is a prime example of how to transform the ineffective system we currently have while simultaneously avoiding much of the controversy between presumed refusal and presumed consent. By eliminating the "presumed" nearly every individual could explicitly state their wishes prior to death. "Under mandated choice, individuals would be required to state their preferences regarding organ donation when they renew their driver's licenses, file income tax forms, or perform some other task mandated by the state." (p. 809) By

enacting mandated choice, it removes the barrier of presumption, and requires that citizens consider their own death and how they feel about organ donation. Often in the cases of presumed refusal and in proposed models of presumed consent, it is the family of the individual that must decide whether or not to donate their organs. Amid the chaos and anxiety that engulfs the family during the death of a loved one, it seems unfair to ask them whether they wish to donate their loved one's organs. By mandating that each person decide for themselves, it spares the family the agonizing decision while simultaneously bolstering the individual's autonomy.

Both presumed refusal and presumed consent seek to respect the autonomy of individuals, but both fail to do so. Regardless of which system is enacted, there will be people whose desires are not met. There will be some who wish to donate, but under a presumed refusal system, their organs will not be donated. Likewise, there will be some who do not wish to donate, but under a presumed consent system, their organs will be donated. Either way, there will be wishes of people violated. By enacting the alternative, mandatory choice, this would not be the case. Each person would be required to explicitly state, legally, their wishes. Not only would this prove to be the most autonomous avenue, if the surveys and polls prove accurate, the number of people willing and able to donate would rise tremendously, thus lessening the gap between the supply and demand for organs. Therefore, mandated choice is the best possible alternative to the organ procurement dilemma because it respects individuals' autonomy, removes family members from making difficult decisions, and raises supply of available organs for transplantation.

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