

Spring 4-14-2015

Presumed Versus Explicit Consent in Regards to Organ Donation

Natalie A. Lamy

Augustana College - Rock Island

Follow this and additional works at: <http://digitalcommons.augustana.edu/ethicscontest>



Part of the [Bioethics and Medical Ethics Commons](#)

Augustana Digital Commons Citation

Lamy, Natalie A.. "Presumed Versus Explicit Consent in Regards to Organ Donation" (2015). *Ethics Essay Contest*.
<http://digitalcommons.augustana.edu/ethicscontest/5>

This Student Paper is brought to you for free and open access by the Prizewinners at Augustana Digital Commons. It has been accepted for inclusion in Ethics Essay Contest by an authorized administrator of Augustana Digital Commons. For more information, please contact digitalcommons@augustana.edu.

Presumed Versus Explicit Consent in Regards to Organ Donation

1. Introduction

Drained, exhausted, and beginning to give up hope. You have been on the waiting list for 8 months, and are running out of time. You lay awake at night waiting for the doctor to rush in with your new heart and tell you that you will be just fine. Unfortunately, the doctors say that there just are not enough heart donors for you to get your much needed heart transplant in time. With this news, you and your family try to mentally prepare and come to terms with your fate. This unfortunate story is one that individuals all over the world hear every day, including in the United States where a name is added to the waiting list every 10 minutes (Organ Donor). According to Alberto Abadie and Sebasten Gay in a 2006 journal, “In 2002, 6679 patients died on the U.S. organ waiting lists before an organ became available, roughly 18 per day” (600). There are currently over 120,000 waiting list candidates (Organ Donation). This number is both alarming and is in need of improvement. Like other countries, the United States currently uses an *explicit consent system* in regards to organ donation, while others use a *presumed consent system*. Some claim a presumed consent system takes away consent, goes against certain religious or cultural values, and lessens the individual’s autonomy. On the other hand, others disagree with an explicit consent system because people do not register to be a donor. While both systems are criticized, I argue that the United States should transition to a presumed consent system because it leads to a larger organ donor pool, many physicians/associations approve, and because it gives opportunity to those suffering on waiting lists. Overall, a presumed consent system, if carefully worked out, would benefit society more than the current explicit consent system.

2. Presumed Consent versus Explicit Consent

There is large difference between an explicit consent system and a presumed consent system. *Explicit consent* means that an individual would need to register as an organ donor, or rather, assumes that no one is an organ donor unless they specifically register themselves as such (Mercer, 10). On the other hand, as defined by Helen Noble in a 2008 journal, *presumed consent* is, “a policy of ‘presumed consent’ would mean that, unless people opted out of the donor register or family members objected, hospitals would be allowed to take their organs” (282). What this means is that every individual is automatically registered as an organ donor. They are, however, given the option to remove their name from the donor list if they wish to do so. Further defined in a 2010 journal in the *Nursing Standard*, “...everyone is placed on the organ donation register unless they ask to be removed. Health professionals would still consult bereaved families on whether they wish their relative’s organs to be donated...” (10). It is important to note that the family is still included in the decision making in a presumed consent system. Including this in the system would be considered a *soft* approach (Mercer, 37). While on the surface these two systems do not seem to differ an extensive amount, they offer vastly different options to individuals. This can lead to controversy in countries in terms of which to go with.

3. What Others are Doing

Which system to use varies from country to country; some prefer presumed consent because it presents new opportunity for more organ donors while others take an explicit route because it makes individuals feel they made the decision on their own. The United States has an explicit consent system. While we do have organ donors in this country, we lack a large pool of them in

comparison to those on waiting lists. In 2013, only 28,953 people received an organ transplant (Organ Donor). Helen Noble cited a quote in her 2008 journal that stated, “Our current organ procurement system relies solely on altruism to motivate donation. Altruism is a fine thing but it is in short supply” (Tabarrok, 2004. Noble 282). Citizens of the United States lack motivation to register as organ donors. Without this motivation, we will not have enough donors to keep up with those on the waiting lists. Lily Mercer perfectly states the underlying issue in her 2013 journal by saying, “...there remains a significant mismatch between organ supply and demand, with ever-increasing waiting lists for transplants” (35). This large gap is believed to be linked to the explicit consent system. Another country with an explicit consent system is the United Kingdom. Mercer comments on their system as having similar issues to the United States by saying, “Public support for organ donation is generally high, with research suggesting that 90% are in favour. However, there remains a gap between expressed desire to donate and registration, with only 29% of adults in the UK on the organ donor register” (38). The United States shows similar results, with 85% of Americans saying they are in favor of donation, 69% saying they would donate after they are deceased, yet only 28% of Americans have granted permission on their license (Abadie, Gay sec. 2). From a utilitarian perspective, an explicit consent system represents standard disposal of a valuable commodity that has the potential to save many lives (Abadie, Gay sec. 1). Clearly there is a disagreement between the preferences people claim and the actual registration for organ donation. To reiterate, there is an issue with an explicit consent system because it lacks getting people to donate.

On the other side of the spectrum is a presumed consent system. Countries that use this type of system include Belgium, Spain, and France. Alberto Abadie and Sebastien Gay stated in a 2006 journal, “In spite of media campaigns and other attempts to promote donation, the supply

of organs cannot keep up with the demand, and the number of patients on waiting lists has been growing steadily during the last decade” (606). This issue became too big for some countries to ignore. Belgium is said to have the best and most efficient presumed consent system, and have seen an increase in the number of available organs because of it (Haroon 230). Belgium’s systems states that if a person is a Belgian national or has lived in the country for over six months, unless they complete a document denying use of their organs or their family objects, they are seen as an organ donor (Portal Belgium). France has also found an increase in organ donation since going to a presumed consent system. Maxwell Mehlman stated a few statistics in his journal: “European experience with presumed consent is frequently cited in support...transplantation has increased since the introduction of presumed consent in France- from 551 to 1808 kidneys; from 15 to 622 hearts and hearts/lungs; from 7 to 409 livers; and from 2 to 43 pancreas” (Sec. 4). Further, Abadie and Gay showed comparisons between countries stating, “Approximately half of the families that are approached to request donation refuse it in the U.S. and Great Britain (informed consent countries), compared to around 20% in Spain and around 30% in France (presumed consent countries)” (sec. 3). All of these statistics seem to imply that a presumed consent system plays a large role in increasing numbers. To further test this, Abadie and Gay did a research study to see if these presumed consent countries had higher donation rates and also if outside factors were the main contributor to the spike. They stated their results as such, “After controlling for other determinants of cadaveric organ donation, we find that countries with presumed consent legislation have higher organ donation rates” (sec. 5). Specifically, countries with a presumed consent system were found to have around 25-30% higher donation rates than those countries that used an explicit consent system (Abadie, Gay sec. 5). These results suggest a presumed consent system has shown real promise in increasing

donors for transplantation purposes for these countries. Finally, Spain also shows higher numbers across the board compared to explicit countries. In 2009, Spain had 34.3 deceased donors per one million people, whereas the United States stood at 26.3 per one million people (Abadie, Gay sec. 1). Overall, the numbers consistently show a positive correlation between a presumed consent system and organ donation.

4. Benefits of Presumed Consent

A presumed consent system originally places every individual on the organ donor list, but they have the option to unregister if they wish. While most individuals say they are accepting of organ donation, the organ supply does not even come close to matching up with the organ demand. Part of the issue may be that people are not registering to be an organ donor because they cannot find the time to do so or are associating it with negative thoughts (i.e. death, having parts distributed, etc.). Having a presumed consent system eliminates this issue and automatically places all of these individuals who wish to donate on the registered list. With more individuals registered, the gap between organ supply and organ demand would shrink and we would see a decline in the waiting lists.

It has also been found to be looked at positively by physicians and others in the medical field. Haroon Ashraf explained what doctors believe in his journal: "Doctors also voted for the introduction of a system of presumed consent for organ donation- but agreed that a public campaign about the merits of organ donation should take place before introducing such a scheme (230). In other words, doctors were for a presumed consent system so long as the public was fully informed and prepared for such a switch. Not only have we found that many doctors approve of a presumed consent system, but in 2008 nurses backed it by two to one at the RCN

Congress (Move to Change Organ Law to Presumed Consent 10). To stick this point more, once England switched to a presumed consent system they found that it attracted public and professional support (Mercer 36). Having both doctors and nurses (and in cases like England, the public) approving a presumed consent system is important to note because these are the individuals who have the most knowledge on medical laws and practices. If they back it up, then it should be looked into more considerably.

Finally, it offers opportunity to other individuals who are suffering and on the waiting list. One of the most powerful examples I have come across of what being an organ donor can do for another is an *ABC News* report titled “Heart-to-Heart.” A young girl named Taylor died in an accident and her parents made the decision to donate her organs because they believed her death would then have meaning. Taylor’s heart was donated to a mother of two who was declining rapidly because she had been on the waiting list for so long. Thanks for Taylor’s donation, this mother will get to see her children grow up and live a normal life. After she was given the heart, Taylor’s mother was able to listen to her daughter’s heartbeat within this mother. This meant more to her than she could have ever imagined because she was able to see just how much this precious gift did for another individual, and also that her daughter had a legacy in the world. This story is a tragedy with a positive spin because a patient was taken off the long waiting list and given a second chance at life. Unfortunately, this is not commonly the case. Patients can wait many years for a transplant and during those years be in constant pain or die before they receive a transplant (Noble 282). If a presumed consent system were put in place, stories like this could be the norm.

5. Rebuttal

Although it seems that a presumed consent system would be the most beneficial, there are many skeptics and critiques. One concern is that it takes away the individuals choice because they are assumed to accept it. Helen Noble quoted in her journal patient concern by stating, “The patient concern watchdog already expressed strong views: ‘We are totally opposed to this. They call it presumed consent, but it is no consent at all. They are relying on inertia and ignorance to get the results that they want’” (282). While I can see where their concern stems from, I do not believe a presumed system takes away consent. A presumed consent system still gives every individual the option to opt-out of being an organ donor. I believe this idea may be from lack of understanding exactly what presumed consent implies; that they unregister as opposed to registering. So long as individuals are fully informed on what the system requires of them to do (register or unregister) then it should be an acceptable system (Neades 268). Further, human beings are creatures of habit. We do not like change because we are afraid of it. However, change does not necessarily mean a negative outcome. A specific example comes from Wales when they changed to a presumed consent system. Once the system was put in place, they found that the public responded quite positively to it (Mercer 36). This may imply that individuals need to have a grace period to adjust to change and then they will be more likely to accept it.

Another critique of a presumed consent system is that it violates certain cultural or religious values. Mercer comments on this by stating, “...cultural and religious views, for example those concerning the sanctity of the human body and the need to prevent unnecessary interference with the body after death, may prevent or discourage some families from providing consent” (38). These individuals fear that a presumed consent system would create conflict with their religious values. On the contrary, this type of system may be beneficial for some who are religious. This system allows for these individuals to opt-out of donating. Maxwell Mehlman

commented on this issue in his journal by saying, “Designing an opting-out system that would enable persons who objected to donation to refuse to donate in a manner that was sensitive to the feelings of patients and their families, that was efficient and cost-effective, and that met religious, ethical and legal requirements” (Sec. 5). Further, it may help those who are in these groups by assisting them in the realization of wishing to be a donor even with the pressure they feel from their respected group (Jacob 295). This is ultimately showing that potential external factors, such as religious or cultural values, may prevent someone who wishes to donate to not. With a presumed consent system, this individual does not have to unregister and will not be judged for it (Jacobs 295).

A third critique of a presumed consent system is that it messes with patient autonomy because their choice is originally made for them. However, as previously stated, 85% of Americans stated they were in favor of organ donation (Abadie, Gay sec. 3). With such a high percentage of the population saying they would be willing to donate shows that they are making an autonomous decision. If they had a presumed consent system, they would be given that choice more readily. This may even help people who wish to be donors but have a mental block in registering to become one. This is best explained by Maxwell Mehlman when he states,

...People are in favor of donation in the abstract, but that psychological factors involved in contemplating their own deaths, or those of their loved ones, make them unable to articulate their true wishes. By eliminating the need to confront donation actively in order to donate, presumed consent might overcome these psychological impediments and allow individuals to give effect to their true beliefs (Mehlman Sec. 4).

This implies that many individuals have a psychological blocker when they have to think about donating their organs after death. Having a presumed consent system would eliminate this blocker if they really wish to be organ donors because they are already registered. This form of system avoids asking the disconcerting question of the individual donating their body (Jacobs 294-295).

Finally, another critique of a presumed consent system is that it makes family members feel they are not a part of the decision making. In other words, families are afraid they will not get a say as to whether or not their loved one donates their organs once passed. Abadie and Gay address this particular concern in their article by stating, “In practice, regardless of the type of legislation and of whether a deceased individual is registered as a donor (or as a non-donor), in most countries families are allowed to have the last word on whether organs will be donated” (sec. 1). The family in their time of need should have a right to voice their opinion and this does not go against a (soft) presumed consent system. Furthermore, Abadie and Gay actually found that having a presumed consent system made families more likely to accept their loved ones wishes and allow them to be a donor than in explicit consent systems (sec. 4). It is important to note that this may make the decision of the deceased individual more meaningful to the family. Sheldon Zink and Stacey Wertlieb stated this perfectly in their article by saying,

Organ donation is an opportunity for the family’s loved one to leave a legacy and become a ‘hero’ to all of those who benefit from the donation. This shift enables the family to understand donation as an incredible opportunity and to concentrate on the family’s ability to turn a terrible situation into something positive and hopeful (131).

Knowing that their loved one wished to help others and also knowing that they are creating opportunity for others to live their lives, may help families understand their decision and stick with that request. Overall, while there are many criticisms of a presumed consent system, there are many factors that may influence or eliminate these concerns within the system.

6. Other Factors

It is important to note that having a presumed consent system is not the sole reason for improved numbers with regards to organ donation. There are other factors that contribute to this increase, such as transplant coordinators, legislation, public attitudes, investments in health care systems, etc. Further, it is essential to specify that I am pursuing the idea of a soft presumed consent system.

Belgium and Spain have some of the most successful presumed consent systems in the world. Both of these countries use transplant coordinators in their intensive care units. These transplant coordinators have specialized training to handle organ donations (Ram, Portal Belgium). They are able to work with the families of the potential donors in a sensitive manner. Statistics show that they have raised rates of families saying yes to the donation (Ram). In fact, in Spain, only about 15% of families refuse organ donation of a loved one compared to 40% in the 1980s and compared to the United States where about half refuse (Ram). Transplant coordinators have thus shown improved numbers in both Spain and Belgium and should be considered in other countries.

A study done in 2009 wanted to look at the impact of a presumed consent system and to identify attitudes of those involved (i.e. public and professionals) (Rithalia et al.). They researched published and unpublished studies on presumed consent systems with regards to

organ donation and compared donation rates between countries. The results showed an increase in all presumed systems and went as followed:

...in Austria the donation rates rose from 4.6 donors (per million people) to 27.2 (per million people) over a 5-year period; in Belgium kidney donation rose from 10.9 (per million people) to 41.3 (per million people) during a 3-year period; and in Singapore kidney procurement rose from an average of 4.7 per year to 31.3 per year in the 3 years after the change in legislation (Rithalia et al.)

While there was a significant increase with a presumed consent system in play, it is still important to note that other factors contribute as well. For example, they found that factors such as transplant capacity and gross domestic product also contributed to the increase in these countries (Rithalia et al.). A combination of factors is necessary for improved numbers; however, switching to a presumed country is a significant factor.

Lastly, I do not intend to imply that I desire a true presumed consent system. A true presumed consent system would mean that the potential donor's decision to stay registered or not would be the final say in regards to their organs. In other words, the family would have no say in the matter. I believe the family should still be included in the process, which would then be considered a soft presumed system. If the family does not feel they have input in regards to a deceased loved one, it may make the already tragic situation worse.

7. Conclusion

In conclusion, organ donation is a difficult subject to address all over the world. While both presumed consent systems and explicit consent systems have their positive and negative aspects, a presumed consent system generally has the most potential for a country to have. A presumed

consent system increases the amount of donors there are, many physicians approve it, and it gives opportunity to individuals on waiting lists. Some critiques of this system claim that it is not really consent, that it violates certain cultural or religious values, that it takes away autonomy, and that it denies the family a say in the decision making. However, this system still gives complete consent to the individual because they still have a choice in whether or not they stay registered. In addition, it does not go against religious or cultural values because the individual can just opt-out of it, and it may also give individuals who wish to donate an easier time doing so who are members of these groups. In regards to autonomy, it still allows the individual to be autonomous because they are given the choice to consent or not and this gives them the final say. Lastly, a presumed consent system would still allow family's to have a say once the individual was deceased, and there is evidence that it helps families see the meaning behind their loved ones initial decision. Overall, while a presumed consent system may cause some concerns, it is the better of the two. I conclude on a quote from Lisa Cherkassky in her 2010 journal when she described a presumed consent system by saying,

It is reasonable and appropriate to assume that most people would wish to act in an altruistic manner and to help others by donating their organs after death...given that the majority of people would be willing to donate, there are good reasons for presuming consent and requiring those who object to donation to register their views. It is more efficient and cost effective to maintain a register of the small number who wish to opt out of donation than of the majority who are willing to be donors. This represents a more positive view of organ donation which is to be encouraged (163-164).

Bibliography

- ABC News*. "Heart-to-Heart." WQAD-8. New York, NY. 23 September 2010. Television.
- Abadie, Alberto & Sebastien Gay. "The Impact of Presumed Consent Legislation on Cadaveric Organ Donation: A Cross-Country Study." *Journal of Health Economics* 25.4 (2006):599-620. *Academic Search Premier*. Web. 1 July 2014.
- Ashraf, Haroon. "Doctor and Patient Groups Vote for Presumed Consent." *Lancet* 354.9174 (1999): 230. *Academic Search Premier*. Web 15 July 2014.
- Cherkassky, Lisa. "Presumed Consent in Organ Donation: Is the Duty Finally upon Us?" *European Journal of Health Law* 17 (2010): 149-164. *Martinus Nijhoff Publishers*. Web. 2 July 2014.
- Jacob, Marie-Andree. "Another look at the Presumed-versus-Informed Consent Dichotomy in Postmortem Organ Procurement." *Journal Compilation* 20.6 (2006): 293-300. *Blackwell Publishing*. Web. 30 July 2014.
- Mehlman, Maxwell J. & Health Matrix. "Presumed Consent to Organ Donation: A Reevaluation." *Journal of Law-Medicine* 1.1 (1999): *Academic Search Premier*. Web. 14 July 2014.
- Mercer, Lily. "Improving the Rates of Organ Donation for Transplantation." *Nursing Standard* 27.26 (2013): 35-40. *RCN Publishing*. Web. 15 July 2014.
- "Move to Change Organ Law to Presumed Consent." *Nursing Standard* 24.46 (2010): 10. *Academic Search Premier*. Web. 1 May 2014.

Nathan, Howard M., Conrad, Suzanne L., Held, Phillip J., McCullough, Keith P., Pieroski, Richard E., Siminoff, Laura A., Ojo, Akinlolu O. "Organ Donation in the United States." *American Journal of Transplantation* 3.4 (2003): 29-40. Blackwell Munksgaard. Web. 30 June 2014.

Neades, Barbara L. "Presumed Consent to Organ Donation in Three European Countries." *Nursing Ethics* 16.3 (2009): 267-282. Sage Publications. Web. 2 July 2014.

Noble, Helen. "Promoting Presumed Consent in Organ Donation." *British Journal of Nursing* 17.5 (2008): 282. CINAHL with Full Text. Web. 1 July 2014.

Organ Donation.. Organ Procurement and Transplantation Network, July 2014. Web. 13 July 2014.

Organ Donor. U.S. Department of Health and Human Services, 2014. Web 13 July 2014.

Portal Belgium. Belgium Federal Government, 2012. Web. 13 July 2014.

Ram, Vidya. "Solving the Organ Crisis, the Spanish Way." *Forbes Investing Newsletter* (2009). *Forbes.* Web. 14 July 2014.

Rithalia A., McDaid, C., Suekarran, S., Nornman, G., Myers, L., & Sowden, A. "A Systematic Review of Presumed Consent Systems for Deceased Organ Donation." *National Center for Biotechnology Information* (2009). *NIHR Health Technology Assessment Programme: Executive Summaries.* Web. 14 July 2014.

Zink, Sheldon & Stacey Wertlieb. "A Study of the Presumptive Approach to Consent for Organ Donation." *Critical Care Nurse* 26.2 (2006). *AACN Journals.* Web. 2 July 2014.