ORGAN PROCUREMENT: AN ETHICAL ANALYSIS IN RELATION TO EMANUEL AND EMANUEL'S FOUR MODELS

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by

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TABLE OF CONTENTS

ACKNOWL	EDGMENTS	iv
INTRODUC	TION	1
CHAPTER		
I.	ORGAN PROCUREMENT	4
II.	AUTONOMY AND THE FOUR MODELS	24
III.	A MODEL FOR ORGAN PROCUREMENT	56
BIBLIOGR A	APHY	73

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INTRODUCTION

Organ donation is the process of removal of an organ from a donor for the reuse in a recipient whose organ is no longer functional. Since the start of organ procurement and donation in 1954, many ethical issues have emerged. A major issue of organ procurement centers around the respect for autonomy of the donor and their family. The United States is suffering from an organ shortage leading to a prioritization of procuring organs over respect for autonomy. In cases of brain death – impossibility of the recovery of all brain stem functions – organs remain viable for donation, leading to the potentiality of the complicated organ donation process. Before consent for organ donation can be obtained, a difficult conversation with the patient's family must be had regarding the circumstances of the patient. The family's decision-making is likely constrained by emotion. How can the family make an autonomous decision when they are subject to internal constraints affecting their decision-making ability?

An analysis of this question started with a description of the process of organ procurement, the history of organ procurement and the ethical issues that have emerged. The first chapter also analyzed the different definitions of death and their implications on organ donation. The first chapter found organ procurement to be a complex process that

¹ Organ donation and transplantation: How it works. Cleveland Clinic. (n.d.). https://my.clevelandclinic.org/health/articles/11750-organ-donation-and-transplantation

² Organ Procurement and Transplantation Network. OPTN. (n.d.). https://optn.transplant.hrsa.gov/data/.

³ Chatterjee, K., Rady, M., Verheijde, J., & Butterfield, R. (2021). A Framework for Revisiting Brain Death: Evaluating Awareness and Attitudes Toward the Neuroscientific and Ethical Debate Around the American Academy of Neurology Brain Death Criteria. *Journal of Intensive Care Medicine*, 36(10), 1149-1166.

varies according to the type of death occurring. Brain death was found to be the most preferable for organ donation as organ viability is highest.⁴

The thesis moved on to a discussion of autonomy, from Kant's moral autonomy to Raz's personal autonomy to Beauchamp and Childress's biomedical autonomy – the current standard of autonomy in bioethics. Beauchamp and Childress focus on what makes an action autonomous. They define acting autonomously as acting with intentionality, understanding and noncontrol.⁵ In 1992, Emanuel and Emanuel proposed four models of physician-patient relationships, highlighting their ideal model.⁶ The three conditions of biomedical autonomy were compared to the four models in the goal of finding a model that could sufficiently boost the autonomy of the family so that they can make an autonomous decision. The analysis found that each model targets a different condition of biomedical autonomy.

Lastly, the difficult conversation of organ procurement was applied to the four models and biomedical autonomy. While Emanuel and Emanuel proposed their models for physician-patient relationships to benefit the patient, this application focused on physician-family relationships to benefit an anonymous third party, i.e., potential organ recipient. In attempting to find a model that could best elevate the family's autonomy, this thesis found that there is no one model that best applies to the organ procurement conversation. Rather, in conclusion, the best model is dependent on whom the physician

⁴ Seifi, A., Lacci, J., & Godoy, D. (2020). Incidence of brain death in the United States. *Clinical Neurology And Neurosurgery*, 195, 105885.

⁵ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104). Oxford University Press.

⁶ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2221–2226.

is conversing with, and which aspect of autonomy needs to be supported. This finding is a deviation from Emanuel and Emanuel's explicit statement that the fourth model is the most ideal.

CHAPTER 1: ORGAN PROCUREMENT

1.1: What is Organ Procurement?

With the intent of saving lives, organ procurement is the process of excision of a viable organ from a donor for the reuse in a recipient's body. Can the donor of the organ be living or dead? This question is dependent on the organ in need. In a living donor, one full kidney, one liver lobe, one lung or part of one lung, part of the pancreas and part of the intestines may be removed for reuse. This is not the case with vital organs – defined as necessary for survival - which include the heart, brain, lungs, liver, and kidney. The surgical extraction of vital organs is morally permissible only after the death of the donor. This ethical requirement is the justification behind the "Dead Donor Rule" (DDR), a moral standard that lays the foundation of organ procurement post-mortem. The DDR is not a law, but rather an ethical norm allowing for the regulation of vital organ donation by necessitating the declaration of the donor's death prior to organ removal for transplantation.

Prior to organ procurement, the type of death in accordance with the DDR must be considered. The category of death that occurs dictates which organs are medically appropriate for harvesting and has its own implications. In order to understand these implications and post-mortem organ procurement, a critical question must be answered – what is the definition of death? In the context of organ procurement, two main

⁷ Donate Organs While Alive | organdonor.gov. (2021).

⁸ Vital Organs. Physiopedia. (2021).

⁹ Truog, R., & Robinson, W. (2003). Role of brain death and the dead-donor rule in the ethics of organ transplantation. *Critical Care Medicine*, *31*(9), 2391-2396.

classifications of death exist: cardiac death (CD) and brain death (BD). Cardiac death is defined as the irreversible cessation of circulatory and respiratory function. The use of "irreversible" is ambiguous with the Institute of Medicine (IOM) listing several interpretations: (1) will not resume spontaneously – without the help of medical technology; (2) cannot be restarted with resuscitation measures; (3) will not be restarted on morally justifiable grounds i.e., wishes of family to withdraw life support. The currently accepted definition of brain death in the United States was proposed by the American Academy of Neurology (AAN) as the impossibility of the recovery of all brain stem functions. Pollowing the cessation of cardiopulmonary activity, life-sustaining organs quickly become unusable for reuse due to rapid ischemia – reduced blood flow. In the case of brain death, a donor who meets the criteria of brain death by the AAN exhibits cardiopulmonary functioning – allowing for the extraction of organs with maximized viability due to less ischemic injury. However, brain death accounts for only 2.06% of all deaths in all hospitals in the United States, with an increasing trend every year.

Prior to the introduction of "brain death," donation after cardiac death (DCD) was the standard. Similar to organ procurement and the DDR, the concept of BD or death by neurologic criteria (DNC), donation after brain death (DBD), CD, and donation after

¹⁰ Reich, D., & Guy, S. (2012). Donation After Cardiac Death in Abdominal Organ Transplantation. *Mount Sinai Journal Of Medicine: A Journal Of Translational And Personalized Medicine*, 79(3), 365-375.

¹¹ Reich, D., & Guy, S. (2012). Donation After Cardiac Death in Abdominal Organ Transplantation. *Mount Sinai Journal Of Medicine: A Journal Of Translational And Personalized Medicine*, 79(3), 365-375.

¹² Chatterjee, K., Rady, M., Verheijde, J., & Butterfield, R. (2021). A Framework for Revisiting Brain Death: Evaluating Awareness and Attitudes Toward the Neuroscientific and Ethical Debate Around the American Academy of Neurology Brain Death Criteria. *Journal Of Intensive Care Medicine*, *36*(10), 1149-1166.

¹³ Seifi, A., Lacci, J., & Godoy, D. (2020). Incidence of brain death in the United States. *Clinical Neurology And Neurosurgery*, 195, 105885.

cardiac death (DCD) remains an ongoing ethical debate among experts and the public, leading to the introduction of new suggestions and definitions of death, as discussed in a later section. Nevertheless, both types of death for the purpose of organ procurement find legal justification with the Uniform Determination of Death Act (UDDA) definition of death. The UDDA allows death to be declared by "either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem."¹⁴

The oversight and regulation of organ procurement in the United States is a complicated multi-level system. Organ procurement is directly supervised by Organ Procurement Organizations (OPO). An OPO is a non-profit legal entity responsible for the recovery of viable organs from the deceased with the aim of increasing the pool of organs for transplantation. There are 57 OPOs in the United States each serving a particular area. The Organ Procurement and Transplantation Network (OPTN) was created to oversee the OPOs, in-part with the Centers for Medicare and Medicaid Services (CMS). The OPTN is governed by the Department of Health and Human Services' Health Resources and Services Administration (HRSA) and United Network of Organ Sharing (UNOS). The arrangement of such a composite organizational structure has produced one of the most fruitful systems of organ recovery and reutilization in the world.

Warnez, M. (2020). The Ethics of Organ Donation after Cardiac Death. The National Catholic Bioethics Quarterly, 20(4), 745-758.

¹⁵ Organ procurement organizations: Increasing organ donations. UNOS. (2021, September 8).

¹⁶ *OPO oversight*. AOPO.

The steady rise of organ procurement and medical advancements with the presence of a widespread managerial system has brought various ethical issues to the surface that require addressing. Before analyzing these ethical issues, I will first discuss the history of organ procurement.

1.2 The History of Organ Procurement

The rise of organ procurement began in the mid-20th century. The world's first successful organ transplant was witnessed on December 23, 1954. The patient was 22-year-old Richard Herrick whose kidneys began to fail after he fell ill while serving a tour of duty on a Coast Guard vessel in the Great Lakes. As his kidneys began to fail, toxins began building up in his blood and poisoning the rest of his body. He was given two years to live. Dr. Joseph E. Murray performed a successful kidney transplant from the patient's identical twin for which he was awarded a Nobel Prize in Medicine in 1990.¹⁷ The field of organ procurement and transplantation saw great progress in the following decades, especially in the 1960's. On June 3, 1963, the first organ was harvested from a brain-dead donor. A patient with a severe head injury was brought to the emergency department of the Saint Pierre Hospital in Louvain, Belgium in comatose condition.

Active resuscitation procedures with the use of vasopressors proved to be futile. Dr. Guy Alexandre, a fellow working under Dr. Murray removed the patient's kidneys with his

¹⁷ Barker, C., & Markmann, J. (2013). Historical Overview of Transplantation. *Cold Spring Harbor Perspectives In Medicine*, *3*(4).

own criteria of BD. Mechanical ventilation was still in place with a beating heart, making this the first instance of DBD¹⁸⁻¹⁹. In December 1966, the first successful kidney-pancreas transplant ever was performed at the University of Minnesota. Dr. William D. Kelly and Dr. Richard C. Lillehei transplanted a kidney and a pancreas in a diabetic patient on dialysis, who received function of both organs.²⁰ Further progress was made in 1967 with the first successful liver transplant performed by the "Father of Transplantation", Dr. Thomas E. Starzl at the University of Colorado²¹ and the first successful heart transplant achieved by Dr. Christiaan Barnard in Cape Town, South Africa²². Following the first heart transplant, the legal groundwork for organ procurement was established in the United States. In the following year of 1968, Congress approved the Uniform Anatomical Gift Act (UAGA) for the regulation of organ and tissue donation²³. This allowed for the development of a widespread organ procurement system in the years to come. During the same year, the Ad Hoc Committee of Harvard Medical School defined brain death as "an irreversible coma" or "loss of brain functions".24 This was the first official definition of BD in the United States – a major milestone, which was updated in the years to come.

¹⁸ Cooper, D. (2021). Guy Alexandre – An appreciation of his innovative contributions to organ transplantation.

¹⁹ Machado, C. (2005). The first organ transplant from a brain-dead donor. *Neurology*, 64(11), 1938–1942.

²⁰ Casanova, D. (2017). Pancreas transplantation: 50 years of experience. *Cirugía Española (English Edition)*, 95(5), 254–260.

²¹ Eghtesad, B., & Fung, J. (2017). *Thomas Earl Starzl, MD, Phd (1926–2017): Father of transplantation*. International Journal of Organ Transplantation Medicine.

²² Brink, J. G., & Hassoulas, J. (2009). The first human heart transplant and further advances in cardiac transplantation at Groote Schuur Hospital and the University of Cape Town - with reference to: The operation. A human cardiac transplant: An interim report of a successful operation performed at Groote Schuur Hospital, Cape Town. Cardiovascular journal of Africa.

²³ Martinez, B. (n.d.). *The Embryo Project Encyclopedia*. Uniform Anatomical Gift Act (1968) | The Embryo Project Encyclopedia.

²⁴ A definition of irreversible coma. report of the Ad Hoc Committee of the Harvard Medical School to examine the definition of brain death. (1968). *JAMA: The Journal of the American Medical Association*, 205(6), 337–340.

Also in 1968, the first independent OPO was developed – the New England Organ Bank – by Dr. Joseph Murray, fourteen years after he demonstrated the first successful organ transplant.²⁵

The 1980's saw remarkable progress in transplantation policies and legality. In 1981, the Uniform Determination of Death Act (UDDA) was established, defining death as either the permanent stoppage of cardiopulmonary functioning or of functioning of the entire brain.²⁶ However, certain ethical issues persisted. Three key issues were combatted at the time. The first issue is the improper allocation of organs. Disadvantaged groups throughout the country were not receiving a fair distribution of organs as compared to their privileged counterparts. The second issue is lack of obtaining proper informed consent from the patient or their family. Patients and their families were not adequately informed about organ donation. Third, patient autonomy was not respected in that the deceased's wishes were not prioritized over the wishes of their family. Progress was made in various acts and amendments to rectify these problems. The first being the National Organ Transplant Act (NOTA) enacted in 1984, which is the foundation for the American transplant system. The act improved the organization of the organ allocation system by maintaining a national registry.²⁷ NOTA also established the Organ Procurement and Transplantation Network (OPTN). To further account for these issues and the progression of organ procurement since the establishment of the UAGA in 1968, the act was revised in 1987 to improve patient autonomy and the process of receiving

²⁵ Our OPO. New England Donor Services. (2021, January 6).

²⁶ Nikas, N. T., Bordlee, D. C., & Moreira, M. (2016, April 20). *Determination of death and the dead donor rule: A survey of the current law on Brain death*. OUP Academic.

²⁷ National Organ Transplant Act enacted 30 years ago. UNOS. (2021, June 17).

consent from the patient or their family. The changes included the Required Request Law which mandates healthcare staff to discuss the opportunity of donating the patient's organs with the patient's family and guaranteeing the priority of a decedent's wishes over the decedent's family members with respect to their objections to organ donation. The last significant accomplishment of the 1980's came on November 27, 1989. A 21-month-old patient suffering from biliary atresia, the most common fatal liver disease in childhood, successfully received a portion of her mother's liver. This was the first living liver transplant, done by a surgical team at the University of Chicago. ²⁹

In 1998, the CMS issued their conditions of participation for hospitals, requiring all hospitals to direct all deaths to the local OPO, promoting organization. The Organ Donor Leave Act which was introduced in the following year of 1999 allowed federal employees to accept paid leave as organ donors. The start of the 21st century saw the authorization of the Children's Health Act in 2000 by President Clinton which modified the NOTA of 1984 to address the needs of children in Title XXI, requiring the OPTN to:

(1) recognize the differences in health and organ transplantation issues between children (individuals under the age of 18) and adults and adopt criteria, policies, and procedures that address children's unique health care needs; and (2) carry out studies and demonstration projects to improve procedures for organ donation procurement and allocation. In 2001, for the first time, the number of living donors passed the number of

²⁸ US Legal, I. (n.d.). *Uniform Anatomical Gift Act of 1987*. Healthcare.

²⁹ Person. (2006, May 24). First living-donor liver transplant recipient graduates from high school May 27. UChicago Medicine.

³⁰ Timeline of historical events and significant milestones. (n.d.).

³¹ Organ donor leave act. CHCOC. (1999, November 2).

³² Text - H.R.4365 - 106th congress (1999-2000): Children's ... (n.d.).

deceased donors in the United States, a significant moment in history. Tommy G. Thompson, former Secretary of the Health and Human Services, launched the Gift of Life program in 2001 with the aim of increasing organ donation by creating registration opportunities for all citizens.³³ In 2002, the OPTN provided live data online on the number of people in line for an organ transplant for the first time. Another issue was identified, this time from the pool of potential donors. It was found that only 43-46% of potential donors end up donating organs. To combat this, the Organ Donation Breakthrough Collaborative of 2003 increased organ donation by promoting better practices by introducing the "change package" in each participating OPO. The change package suggested beneficial activities such as guiding teams in identifying organ donation champions within hospitals who can help overcome barriers, increasing visibility of OPO staff within donor hospitals, and educating hospital staff on clinical triggers in very ill patients that warrant referral to the OPO. 34 To further establish the importance of organ donation, the Organ Donation and Recovery Improvement Act was approved in 2004, achieving three major things: (1) directing the Secretary to establish a public education program to increase awareness about organ donation and the need to provide for an adequate rate of donations, (2) allowing living organ donors to be financially compensated for their travel and living expenses, (3) directing the Secretary to report on organ donation and recovery activities. 35 Still, patient autonomy was not being properly respected. So, for the second time, the UAGA was revised, this time in 2006.

³³ Timeline of historical events and significant milestones. (n.d.).

³⁴ Spreading the gift of Life: Organ Donation Breakthrough Collaborative: IHI. Institute for Healthcare Improvement. (n.d.).

³⁵ Cosponsors - H.R.3926 - 108th Congress (2003-2004): Organ ... (n.d.).

The aims of the 2006 revision included an increase in organ donation and placed an emphasis on respecting the deceased and their wishes. Further ethical progress was made by the Institute of Medicine in 2006. By forming a committee of fourteen experts, the IOM released a report titled "Organ Donation: Opportunities for Action", based on four fundamental principles: (1) the need for a trustworthy system to support organ donation, (2) the increase of appeal for organ donation based on motivations such as altruism, (3) the respect of patients and their wishes and beliefs as well as the respect of the family's wishes, (4) the further promotion of fairness in organ distribution. The proposals put forth by the committee included financial incentives to support groups in need, emphasizing that all members of society deserve the opportunity to receive an adequate supply of organs as all individuals are potential donors and potential recipients, strengthening efforts to educate the public about the benefits of organ donation, and the continuation of improving donation systems.³⁶ Another issue of organ procurement was addressed by a major movement was seen in the 2000s. The discrepancy between organs in need and organs available has caused a major organ shortage in the United States. The Donor Designation Collaborative (DDC) was introduced by Donate Life America in 2006 with the purpose of combatting the nationwide organ shortage. The main strategy to accomplish this was to ensure that each state has an effective system for allowing individuals to legally designate themselves as donors. The goal was to increase the

³⁶ Childress, J. F., & Liverman, C. T. (2006). Organ donation: Opportunities for action. National Academies Press.

number of registered donors in the United States to one hundred million. This goal was achieved in 2011.³⁷

The 2010s witnessed 155,643 organ donations, a 13.3% increase from the 137,391 donations in the previous decade. As of 2020, an outstanding 169 million Americans are registered to donate organs. The United States continues to make progress in organ procurement, continuously breaking records. However, pressing ethical concerns persist today including the issues of fair allocation and patient autonomy that previously discussed acts and amendments attempted to resolve. In the following section, I will elaborate on the mentioned ethical concerns along with further moral dilemmas that trouble organ procurement which have risen from the extensive history aforementioned.

1.3 The Ethical Issues

The advancement of organ transplantation and medical technology since the 1950's has introduced many ethical questions. The establishment of the DDR calls for the death of the patient before the procurement of vital organs. Objection to the DDR has emerged with scholars defending the intentional killing of a patient for the procurement of their organs. The argument is based on the quickly deteriorating condition of organs following death. Robert Truog is one such scholar who challenges the DDR. Truog argues that organ procurement prior to the death of the patient is justifiable when valid

³⁷ Donate Life America. (2011, October 11). *Donate Life America announces 100 millionth organ, eye and tissue donor registered in the U.S.* Donate Life America.

³⁸ Organ donation statistics. (n.d.).

consent has been obtained from the patient or their surrogate. ³⁹ With appropriate consent, Truog argues that there is no significant distinction between death caused by procurement and death from withdrawal of life support. In other words, Truog wants to treat "might as well be dead" and "dead" as the same to increase organ procurement opportunities.

Treating these two groups as the same would also provide clarity for the purpose of public policy. Naturally, this position has been met with controversy and raises the topic of non-interference. If a patient or their surrogate wishes to end life support, assuming competency - assessed by a mental status examination to assure the ability to understand medical situations and make medical decisions - this must be respected regardless of the need for organ donation. Nevertheless, a competent patient or surrogate would not be allowed to request a treatment or procedure, including the excision of a vital organ, making death by organ procurement impractical. Admittedly, Truog states that the formulation of a policy or law consistent with this argument is unlikely.

The widespread acceptance of the DDR brings up an ethical question relating to a fundamental concept of organ procurement that has created an ongoing debate – what is the definition of death? In order to determine the morality of organ procurement postmortem, death must be defined. Thus far, death has been looked at from a biomedical perspective. However, is a background in medicine needed to be able to define death? By rephrasing the question of death into a philosophical question, any competent person can define death – what qualities in a human are significant enough that the loss of these

³⁹ Truog, R. and Miller, F., 2008. The Dead Donor Rule and Organ Transplantation. *New England Journal of Medicine*, 359(7), pp.674-675.

qualities deems a human as no longer part of the human community?⁴⁰ Perhaps, only after this question is answered should death be looked at from a medical aspect. It appears the point at which a patient should be treated as dead is not a medical question, but rather an evaluative one.

Barbara B. Ott illustrates the three widely accepted medical definitions of death in the United States. ⁴¹ The first definition is heart-lung death, the long-accepted standard until the introduction of BD in the 1960's. The cessation of cardiac activity and consequential pulmonary functioning following the failure of medical intervention constitutes heart-lung death. Veatch illustrates two categories of circulatory death, "unplanned" and "planned". ³³ Unplanned CD refers to sudden cases of heart attacks leading to cardiac arrest whereas planned CD is cardiac arrest caused from the withdrawal of life support in patients being treated for critical conditions. These two types of CD are usually considered as one, although each type has different implications. As such, the probability of procuring viable organs in cases of unplanned CD is significantly lower than cases of planned CD due to the emergent nature of the former.

By further relating heart-lung death to organ procurement, multiple ethical questions and issues emerge. With the advancement of medicine, the ability to artificially support impaired organs became possible, including the heart and lungs. This implies that the traditional heart-lung definition of death does not properly account for the ethical

⁴⁰ Veatch, R., & Ross, L. (2015). *Transplantation ethics*. Georgetown University Press.

³⁶ Ott, B. B. (1995). Defining and redefining death. *American Journal of Critical Care*, 4(6), 476–480.

questions that arise from the use of technology to sustain bodily functions. Still, defenders of heart-lung death such as religious groups argue that death is only defined after respiratory and circulatory functioning fail independently of the use of medical technology. Robert M. Veatch highlights a study showing around 10% of Americans defending the heart-lung definition of death.³³ To better explain the ethical questions caused by this definition of death, let's consider an example: a patient is in a vegetative state with active cardiopulmonary functioning that exists due to modern technology. However, they lack adequate neurological activity to support life without the use of technology. Is this patient supposed to be treated as dead or alive? According to the heart-lung definition, this patient is alive, but if death is inevitable then what practices are acceptable? Is the use of life-prolonging technology the difference between life and death? How long are life-sustaining measures supposed to continue? Such questions prompted the need for a new definition of death, one that is applicable with current practices in modern medicine.

When the Ad Hoc Committee of the Harvard Medical School established a new definition of death in 1968, they aimed to clarify these questions and help hospital overload. Their definition of death is described as "whole-brain death", an irreversible coma consistent with unreceptivity, unresponsivity, lack of movement, breathing and reflexes.⁴² Essentially, the lack of integrative function of the brain as a whole results in

⁴² A definition of irreversible coma. report of the Ad Hoc Committee of the Harvard Medical School to examine the definition of brain death. (1968). *JAMA: The Journal of the American Medical Association*, 205(6), 337–340.

death. This definition allowed for the stoppage of treatment to be justifiable, increasing procurement opportunities and allowing the opening of more resources such as beds. Still, this definition has sparked controversy. As illustrated by Veatch, the 1968 explanation of death offers vague insight into what actually BD is, but rather details the concept of an irreversible coma. 43 Should it be assumed that "brain death" and "irreversible coma" are interchangeable? As mentioned previously, the use of "irreversible" fails to provide adequate clarity. Irreversibility can be interpreted as a moral or medical topic. From a moral perspective, irreversibility arises when life support is no longer continued due to the wishes of the family. Alternatively, an individual with a medical background would argue that irreversibility is only defined when the preservation of life-sustaining functions is no longer possible with use of medical technology or interventions. Moral irreversibility should take priority as a failure of respecting this hierarchy results in ethical issues such as a lack of respect for autonomy along with legal issues. Further issues are introduced by the Harvard definition of death. What about specific types of brain functioning that are still active but non-vital, such as endocrine function? Another problem with the definition of whole-brain death arises with near-death cases. Suppose a patient can exhibit a weak motor response to pain stimuli but is still in the state of an "irreversible coma", meaning death is inevitable. The whole-brain definition of death states that this patient is still alive, but again, how can this be the distinction between life and death? Should this distinction be looked at from a normative

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⁴³ Veatch, R. M. (2018). Would a reasonable person now accept the 1968 Harvard Brain Death Report? A short history of brain death. *Hastings Center Report*, 48.

or medical standpoint? And still the question remains, how should this patient really be treated – as "alive", "might as well be dead" or "dead"? It appears the first two medical definitions of death require further modification with the aim of providing better insight and suitability for organ procurement.

Before discussing the third widely accepted definition of death – higher-brain death, it is important to first elaborate on the interplay of CD and BD and the relation to DCD. When determining BD, the heart-lung definition can be used a measure of death but should not be the final indicator. This is because the cessation of cardiopulmonary functioning does not always determine BD. There are instances in which the loss of circulation for a few minutes can be reversed, meaning brain function is still present – to a certain extent. By treating circulatory death as an indirect indicator of BD, another question is born that requires more attention – for low long after the loss of cardiopulmonary functioning can a patient exhibit neurological functioning? Conflicting research studies answering this question have shown a wide range of time periods – from two seconds up to five minutes. He appears that the expected nature of planned CD. This raises the discussion of determining DCD. There are two methods in which DCD is established with the first previously mentioned: time after the loss of cardiopulmonary functioning (1) after which

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⁴⁴ Dreier, J. P., Major, S., Foreman, B., Winkler, M. K., Kang, E.-J., Milakara, D., Lemale, C. L., DiNapoli, V., Hinzman, J. M., Woitzik, J., Andaluz, N., Carlson, A., & Hartings, J. A. (2018). Terminal spreading depolarization and electrical silence in death of human cerebral cortex. *Annals of Neurology*, 83(2), 295–310.

⁴⁵ Parnia, S., Spearpoint, K., de Vos, G., Fenwick, P., Goldberg, D., Yang, J., Zhu, J., Baker, K., Killingback, H., McLean, P., Wood, M., Zafari, A. M., Dickert, N., Beisteiner, R., Sterz, F., Berger, M., Warlow, C., Bullock, S., Lovett, S., ... Schoenfeld, E. R. (2014). Aware—awareness during resuscitation—a prospective study. *Resuscitation*, 85(12), 1799–1805.

BD is achieved and (2) after which such circulatory functioning cannot be reversed, independent of brain function. In the case of the first method, the conflicting research evidence of the duration in which a donor is pronounced as brain-dead following loss of circulation leads to yet another issue. Basically, the lack of a definitive period of time after which a patient loses cardiopulmonary functioning that they are confirmed braindead, leads to an inconsistent and potentially inaccurate measure of true CD. A defender of the second method would argue that circulation is fundamentally important in the determination of death, but the same problem remains. The second method also lacks a conclusive duration of time, as there is no definitive time in which cardiopulmonary functioning stops that the loss of circulation is deemed as irreversible. Without definitive guidelines on a time period in both cases, organ procurement following CD becomes less fruitful. To explain how this is caused, it is important to know that different hospitals follow different durations following the loss of circulation. More conservative hospitals adhere to longer durations of time than other hospitals. As such, this extended period reduces the viability of organs, making organ procurement impossible in many cases. Regardless of where one stands with these two methods, a significant problem remains with DCD and organ procurement as a whole – organ shortage. In many cases, organs are unusable for transplantation in patients falling under CD. The OPTN highlights the seriousness of the nationwide organ shortage. As of October 27, 2021 – 106,670 waiting list members exist with only 15,330 organs procured from January to September 2021.⁴⁶

⁴⁶ Organ Procurement and Transplantation Network. OPTN. (n.d.). https://optn.transplant.hrsa.gov/data/.

This disparity may very well be explained by DCD due to a lower viability of organs from an extended stoppage of blood flow as compared to DBD and by the lower number of DBD cases. The problematic nature of DCD does not end there. DCD also challenges the definition of death introduced by the UDDA in 1981. The UDDA states two classifications of death: either the permanent stoppage of cardiopulmonary functioning or functioning of the entire brain. Now, with the knowledge of the relationship between CD and BD, it is apparent that CD is not the most ideal way to determine death for organ procurement, especially from the interest of increasing the organ pool. This calls for an alteration in the definition of death by the UDDA to exclude CD for better applicability.

Under the classification of whole-brain death, an individual must have integration of vital functioning or any form of brain activity to be considered as living. As mentioned, this raises questions such as "is one non-vital brain function simply the difference between life and death?" This leads to the third and final widely accepted definition of death - higher-brain death, a philosophical modification of whole-brain death. Instead of only accounting for the functioning of the body, the higher-brain definition of death incorporates the mind. Veatch argues that the integration between body and mind is what makes us human. Essentially, the capacity to experience the world through one's own body inclusive of social interactions is what defines someone as alive. The experiences built through interactions with the world defines humanness. Without the ability to do so, there would be nothing defining us as human, as Veatch argues. He proposes the definition of death as an irreversible loss of the embodied capacity for

consciousness.⁴⁷ Additionally, this definition of death accounts for the progression of medical technology and helps to combat the organ shortage. With the progression of medicine, we are seeing more body parts being replaced. It is clear that the higher-brain definition of death only discusses the death of what makes an individual unique which is undeniably irreplaceable by medical advancements (for the foreseen future). With the alteration of the whole-brain definition to account for "critical" brain functioning rather than the functioning of the brain as a whole, more opportunities for organ procurement are introduced. In many cases, while a patient is dead under the definition of higher-brain death, they still exhibit cardiopulmonary functioning and other brain functioning.

Therefore, the cessation of only neocortical functioning – responsible for humanness – increases the viability of organs due to a minimal stoppage of fluid flow. This implies that DBD is favorable over DCD from a utilitarian perspective. It is evident that this definition of death better explains the distinction between life and death than the previous definitions while also accounting for the scarce organ supply in an improved manner.

Naturally, due to the comparatively abstract definition of higher-brain death, criticism exists. From a medical perspective, the higher-brain classification of death is inapplicable in many cases. A patient lacking neocortical functioning may very well exhibit some biological aspects of life such as breathing. Such a patient is considered dead under the higher-brain death definition, but since they are capable of vital biological

⁴⁷ Veatch, R. M. (1988). Whole-brain, neocortical, and higher brain related concepts. *Death: Beyond Whole-Brain Criteria*, 171–186.

functioning, they are living. Also, the classification of an individual as dead when they lack the ability to interact with the environment and others leads to the exclusion of certain groups. As Ott discusses, severely mentally ill individuals who lack the capability of "higher-brain function" would be considered dead despite showing biological functioning, which would again be morally impermissible.³⁴ Also, it is highly unlikely that a societal acceptance of classifying an individual as dead when they show the biological signs of life will be achieved. Besides the lack of social and legal basis, further complications exist regarding higher-brain death.

The tests used to determine whole-brain death – ancillary tests – are not as effective in confirming higher-brain death. Testing the death of the brain as a whole is much more straightforward than testing for the inactivity of a specific part of the brain. Currently, there is no testing that can accurately determine higher-brain death, making higher-brain death impractical. Until a positive change in practicality is made through the development of medical technology, higher-brain death should not be accepted.

The ethical issues that have emerged since the rise of organ procurement in the second half of the 20th century persist today. The need of respecting patients and the need of more organs has led to an autonomy vs utilitarianism divide in the field of organ procurement. To improve organ procurement practices today, the introduction of a model promoting better autonomy with an adequate satisfaction of the utilitarian view would be beneficial. In 1992, Emanuel and Emanuel introduced four models of the physician-patient relationship. I believe relating their models to the ethics of organ procurement would be significant in developing a new model. Having set the groundwork of the ethics

of organ procurement, I will discuss the four models of the physician-patient relationship proposed by Emanuel and Emanuel before applying their models to present day organ procurement.

CHAPTER 2: AUTONOMY AND THE FOUR MODELS

2.1: A History of Autonomy

As discussed in the previous chapter, the twentieth century illustrated the need for a standard that better reflects the ethical ideals of modern organ procurement. Historically, the relationship between a physician and patient has been physiciandominant with the majority, if not all the control in the physician's hands. The moral awakening of the past century called for a more balanced power division between the physician and patient, and greater respect for patient autonomy. This sparked a major ongoing debate in bioethics between two opposing fundamental themes: *autonomy* vs *paternalism*. Before discussing this debate, the definitions of *autonomy* and *paternalism* and their meaning in bioethical settings must be analyzed, starting with autonomy.

The concept of 'autonomy' originated in ancient Greece with "auto" meaning "self" and "nomos" meaning "law" or "rule", making the literal definition of autonomy "self-ruled". Autonomy is a multi-dimensional concept with many interpretations in different contexts, but simply put is the general condition of self-governance.⁵¹ In the context of organ procurement and medical ethics, the notion of autonomy put forth by

⁴⁸ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2221–2226.

⁴⁹ Siegler, M. (1985). Who Should Decide?: Paternalism in Health Care, by James F. Childress. *Perspectives In Biology And Medicine*, 28(3), 452-456.

⁵⁰ Christman, J. (2020, September 21). *Autonomy in moral and political philosophy*. Stanford Encyclopedia of Philosophy.

⁵¹ Killmister, S. (2017). *Taking the measure of autonomy: A four-dimensional theory of self-governance* (1st ed.). Routledge.

Thomas Beauchamp and James Childress is considered the standard. They established a framework of four vital principles that lie at the heart of moral reasoning in healthcare in their multiple editions of *Principles of Biomedical Ethics*. ⁵² The first principle is the *respect for autonomy* where Beauchamp and Childress present autonomy as a three-condition theory. Prior to analyzing this conception of autonomy, two types of autonomy will be discussed to illustrate the evolution of autonomy as understood today – *moral autonomy* and *personal autonomy* – starting with the traditional concept of moral autonomy.

Immanuel Kant is thought to have introduced the theory of moral autonomy with his moral philosophy in the 18th century.⁵³ The main idea of the Kantian moral theory is that to act morally is indistinguishable from acting rationally.⁵⁴ To Kant, acting with rationality means acting in accordance with the *moral law*. Kant argues that rational individuals are bound to this moral law equally as they all share the same capability to act according to principles, otherwise known as practical reason.⁵⁵ Acting differently from what is prescribed by the moral law would be considered irrational. Kant stresses the importance of rational individuals complying with the moral law, but what is this moral law? Kant regards the moral law as the absolute standard of moral requirements that hold their validity under all circumstances and must be followed regardless of any internal

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⁵² Beauchamp, T. L., & Childress, J. F. (2019). *Principles of Biomedical Ethics*. Oxford University Press.

⁵³ Christman, J. (2020, September 21). *Autonomy in moral and political philosophy*. Stanford Encyclopedia of Philosophy. https://plato.stanford.edu/entries/autonomy-moral/#AutPat

⁵⁴ Williams, G. (2018, June 21). *Kant's account of Reason*. Stanford Encyclopedia of Philosophy. https://plato.stanford.edu/entries/kantreason/#FreImpMorConForCatImp

⁵⁵ Britannica, T. Editors of Encyclopaedia (2009, April 20). *practical reason. Encyclopedia Britannica*. https://www.britannica.com/topic/practical-reason

desires or external factors.⁵⁶ This implies that these moral requirements apply to us unconditionally and as a result, they are deemed universal, and therefore the moral law is as well. The moral law is determined by Kant's universal ethical principle: the *categorical imperative*.⁵⁷ It is *categorical* because it applies to us unconditionally and *imperative* because it is a command. The categorical imperative is concerned with the principle behind an action and presents a process for determining whether an action is in accordance with the binding moral law, that is, the moral status of an action.⁵⁸ This process is explained by the principle of universalizability otherwise known as the original formulation of the categorical imperative in which Kant says, "act only in accordance with that maxim through which you can at the same time will that it become a universal law." Here, a maxim is a rule determined by a subjective principle of acting where that action is connected to the reasoning behind the action.⁵⁹ An example of a maxim would be "I ought to not litter to keep the environment clean." What Kant means in his first formulation is that we should act as if our actions will become a universal law of nature.

Kant's moral theory is elaborate, but how does he use his theory to define moral autonomy? We have seen that an individual with rationality only makes decisions they deem as morally worthy by using the moral law to determine what actions are moral.⁶⁰ In other words, acting with rationality means acting in response to practical reason or in

⁵⁶ Williams, G. (2018, June 21). *Kant's account of Reason*. Stanford Encyclopedia of Philosophy. https://plato.stanford.edu/entries/kantreason/#FreImpMorConForCatImp

⁵⁷ Johnson, R., & Cureton, A. (2016, July 7). Kant's moral philosophy. Stanford Encyclopedia of Philosophy.

⁵⁸ Kant, I., & Gregor, M. J. (1996). *Practical philosophy* (p. 72). Cambridge University Press. ⁵⁹ Kant, I., & Gregor, M. J. (1996). *Practical philosophy* (p. 73). Cambridge University Press.

⁶⁰ Christman, J. (2020, September 21). *Autonomy in moral and political philosophy*. Stanford Encyclopedia of Philosophy. https://plato.stanford.edu/entries/autonomy-moral/#AutPat

accordance with the moral law. Since the moral law applies to us unconditionally, it is universal. This universal law is formed by acting on our own rationality, therefore, we self-impose the moral law. This self-imposition of the universal *moral* law is called *moral* autonomy.⁶¹ Kant's notion of autonomy formally says, "the property of the will by which it is a law to itself independently of any property of the objects of volition".⁶² In summary, the Kantian conception of autonomy describes the capacity of a rational being to independently govern oneself.

2.2: From Moral Autonomy to Personal Autonomy

Around the same time Kant was writing about his notion of autonomy, the industrial revolution was taking place. The revolution is responsible for the rapidly evolving technological age we live in today. With changing social, economic and technological conditions and views in the modern world, individuals are expected to adapt and develop. As a result, a greater emphasis on the importance of the individual has been placed. This principle is known as individualism and asserts an individual's moral or intrinsic worth. This is described by the second formulation of Kant's categorical imperative, otherwise known as the Humanity Formulation. It states, "so act as to treat humanity, whether in your own person or in that of any other, in every case as an end and never as merely a means." Kant holds that humans have an immeasurable intrinsic value due to their capability to their ability to reason. As such, individuals are valuable in and

⁶¹ Christman, J. (2020, September 21). *Autonomy in moral and political philosophy*. Stanford Encyclopedia of Philosophy. https://plato.stanford.edu/entries/autonomy-moral/#AutPat

⁶² Darwall, S. (2006). The value of autonomy and autonomy of the will. *Ethics*, 116(2), 263–284.

⁶³ Lukes, S. M. (2020, January 14). *individualism*. *Encyclopedia Britannica*.

of themselves and are meant to be treated with respect, and not simply used for personal gain.⁶⁴ For example, a patient *using* their physician as a *means* to receive treatment is not a violation of the second formulation. This is because the patient is not *merely* using their physician for their benefit, but rather treats them as ends in and of themselves by paying for their medical bills which allows the physician to be paid for their work.

The growth of individualism in the modern world has shifted the focus of autonomy from Kant's notion of self-governance and intrinsic value to a conception of individual well-being. This has led to a modern notion of autonomy that has gained a significant amount of popularity – *personal autonomy* or *individual autonomy*. The main idea behind personal autonomy is that individuals should be the author of their lives.

Otherwise put, an autonomous individual is one who controls the outcome of their own destiny through personal decisions made with the freedom to do so. Since these decisions are personal, it can be said that they are made with one's *authentic desires*, values, or goals. Acting with an authentic desire is the same as acting with higher-order volition or second-order desires which result from the additional capacity to rationally evaluate first-order desires. While second-order desires are desires about first-order desires, first-order desires are desires about anything else. To rexample, wanting to smoke a cigarette is a first-order desire and wanting to not want to smoke a cigarette is a

⁶⁴ Kerstein, S. (2019, June 21). *Treating persons as means*. Stanford Encyclopedia of Philosophy. https://plato.stanford.edu/archives/sum2019/entries/persons-means/

⁶⁵ Raz, J. (1986). Personal Autonomy. In *The morality of freedom* (p. 369). Clarendon Press.

⁶⁶ Loughrey, D. (1998). Second-order desire accounts of autonomy. *International Journal of Philosophical Studies*, 6(2), 211–229.

⁶⁷ Schroeder, T. (2020, June 21). *Desire*. Stanford Encyclopedia of Philosophy. https://plato.stanford.edu/entries/desire/

second-order desire. Through rational evaluation of the first-order desire, the second-order desire was formed.

I will present two perspectives on personal autonomy, the first offers a general view of personal autonomy, while the second is the standard of autonomy used in bioethics. The first perspective of personal autonomy comes from Joseph Raz and allows us to reach to an initial conclusion. If an individual were to achieve personal autonomy, what would be required? According to Raz in his discussion of personal autonomy, there are three distinct conditions for an individual to be their own person: (1) appropriate mental conditions, (2) an adequate range of options and (3) independence. ⁶⁸ By "appropriate mental conditions", Raz is referring to a minimum level of rationality – this time as the capability in forming intentions and planning actions – required to control one's own destiny. The second condition is "an adequate range of options". When Raz says "adequate range", he means the variety of options when deciding towards a goal should include long term and short-term options. For example, a person held hostage with access to only limited food and water only has short-term options. These include eating now or later and sleeping now or later. Raz argues that such a person with lack of an adequate range of options possesses a lack of control over their life. Therefore, according to Raz, this person cannot be the author of their own life and lacks personal autonomy. The last condition of personal autonomy is "independence". Raz understands independence in the form of coercion and manipulation. Both oppose the free will but differently. Coercion is the force on an individual into making into a particular decision

⁶⁸ Raz, J. (1986). Personal Autonomy. In *The morality of freedom* (pp. 372–373). Clarendon Press.

and can limit the number of options an individual possesses. Manipulation is the control of an individual and interferes with how they reach decisions.⁶⁹ For an individual to be independent, they must be without coercion and manipulation.

From a brief discussion on Raz's conception of personal autonomy, an example can be used to elucidate the relation between moral autonomy and personal autonomy. Let's consider a man with a financially dependent family who has endured a devastating monetary loss following a night of gambling. The man's financial loss is to the extent that he and his family are in jeopardy of homelessness. On his return home, he notices a hefty amount of money in a bag on the street. The sum of money appears to be enough to lift the man out of immediate financial trouble. The bag is sitting near a homeless person who is asleep, appearing as if the bag very well belongs to them. The man could take the bag with no witnesses if he wishes. The man has two options here: (1) take the money to use as his, and (2) leave the bag of money where it sits. How does he act? Now, if this man were to act with moral autonomy, he would act in accordance with the moral law. Since the act of stealing is not universalizable – if everyone stole, no one would have a fixed personal value – the moral law would deem this action as morally impermissible. Therefore, if the man is acting with moral autonomy, he would leave the bag of money. Alternatively, suppose this man is acting with personal autonomy. Now, there are multiple similarities between acting with moral autonomy and personal autonomy: persons must be able to conceptualize themselves as selves among other selves, understand their own attitudes and motivations, grasp the nature of situations they face,

 $^{^{69}}$ Raz, J. (1986). Personal Autonomy. In *The morality of freedom* (p. 377). Clarendon Press.

reflect on, and compare alternatives for choice, and make choices that accord with their own relevant attitudes. 70 However, an individual acting with personal autonomy makes decisions based off their authentic desires. Let's look at two scenarios. In the first, the man's authentic desire is to claim the sum of money to boost his troubled financial status. Since personal autonomy links decisions to authenticity and not moral obligation, the morality of the situation can be ignored. This enables the man to claim the sum of money. In the second scenario, the man's authentic desire is to act out of moral obligation and therefore, leave the money. This second case highlights the key difference between personal autonomy and moral autonomy. That is, individuals acting with personal autonomy can act based on moral and nonmoral norms whereas acting with moral autonomy can *only* be done on the basis of moral norms. Therefore, there is the perspective that moral autonomy exists as one variety of personal autonomy.⁷¹ Particularly, the variety that *only* regards morality. We can say that personal autonomy evolved from moral autonomy and has become a broader classification of autonomy in which moral autonomy is a part. In viewing moral autonomy as a variety of personal autonomy, we can now think of *autonomy* as one notion – personal autonomy. This uncomplicated perspective will set the foundation for the meaning of *autonomy* in medical ethics and will allow for a more coherent discussion.

⁷⁰ Friedman, M. (2003). Autonomy, gender, politics (p. 63). Oxford University Press.

⁷¹ Friedman, M. (2003). *Autonomy, gender, politics* (p. 67). Oxford University Press.

2.3: Autonomy in Biomedical Ethics

Until now, autonomy has been examined in a general sense. However, what is the understanding of *autonomy* in the setting of biomedical ethics? Discussed in the previous chapter, the twentieth century ethical landscape of medicine showed the drastic need for improvement. In light of this, Thomas Beauchamp and James Childress established a framework of four bioethical principles that builds the core of moral reasoning in healthcare. Their ethical formulation is the standard for biomedical ethics. The first principle they introduce is the *respect for autonomy*. It is important to note that Beauchamp and Childress do not assign the highest priority to this principle, but rather chose to present it first in their discussion.

The field of medical ethics encompasses a broad range of circumstances and an assortment of patients that vary from age to decision-making ability. The extensive nature of medicine necessitates the expansion of the scope of autonomy to include the wide range of patients and cases. To achieve this, it must be assumed that the everyday choices of generally competent persons are autonomous. Also, the focus of autonomy must be shifted from self-governance to autonomous choice. This is because the presence of the capacity to self-govern does not always assume autonomous choices. An autonomous individual may be victim to controlling influences such as disease or manipulation that disrupt their authentic decision-making, labeling a choice made under these conditions as nonautonomous. Similarly, just because an individual is generally considered incapable

⁷² Toulmin, S. (1988). Medical ethics in its American context. *Annals of the New York Academy of Sciences*, 530(7), 7–15.

⁷³ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104). Oxford University Press.

of making autonomous decisions does not deem all their choices as nonautonomous. For example, a mentally ill patient who cannot live independently could still be capable of making autonomous choices such as deciding when to sleep and what to eat. Instead of focusing on the ideals of autonomy, Beauchamp and Childress build their theory on nonideal conditions, allowing for a more inclusive approach. They describe three conditions for an action to be considered autonomous. While the three conditions put forth by Raz's general theory of personal autonomy were *appropriate mental abilities*, *an adequate range of options*, and *independence*, the Beauchamp and Childress conditions include *intentionality*, *understanding*, and *noncontrol*. T5-76

The first condition for an individual to be considered autonomous is *intentionality*. There is a distinction between *authenticity* and *intentionality* which is important for the appropriacy in biomedical ethics. In the previous discussion of autonomy, it was seen that autonomy links decisions to authenticity. As discussed, for a decision to be authentic, it must be done by rationally evaluating a first-order desire to form a higher-order desire and agreeing with that higher-order volition. The example of the smoker presented earlier illustrates the difference between a first-order desire and higher-order desire. Wanting to smoke a cigarette is a first-order desire and wanting to not want to smoke a cigarette is a second-order desire. Through rational evaluation of the

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⁷⁴ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104). Oxford University Press.

⁷⁵ Raz, J. (1986). Personal Autonomy. In *The morality of freedom* (p. 372). Clarendon Press.

⁷⁶ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104). Oxford University Press.

⁷⁷ Loughrey, D. (1998). Second-order desire accounts of autonomy. *International Journal of Philosophical Studies*, 6(2), 211–229.

first-order desire, the second-order desire was formed. Beauchamp and Childress argue that including this condition of authenticity leads to a theory of biomedical autonomy that is too narrow, limiting the spectrum of actions considered autonomous. The requirement of rationally evaluating desires for an action to be autonomous excludes actions that would almost always be treated as autonomous, such as the decision to watch television without reflection on one's desire to do so. Acting with authenticity also means acting in agreement with one's established values, and their desires and wants.⁷⁸ This condition of authenticity can limit the scope of actions by posing two problems. First, in medicine, autonomous choices can be made by acting in opposition to one's values. For example, a patient holding curative values, that is, the belief that the treatment of the illness takes priority may make a decision based on palliative values – prioritizing relief and comfort over treating and curing – to improve their quality of living. The patient is acting in contradiction to how they would normally act. Simply because an individual makes a decision based on values they normally would not hold; their decision cannot be deemed as nonauthentic or nonautonomous. The second problem brings us to the distinction between authenticity and intentionality. The motivation behind an action is often of conflicting wants and desires but does not represent a less intentional action. A patient could be unsure of which treatment to seek, but their uncertainty does not make their decision any less intentional. Rather, Beauchamp and Childress focus on the planning behind an action – a specific aspect of *authenticity* that is appropriate for biomedical ethics, called *intentionality*. For an action to be deemed intentional, it must be done with

⁷⁸ Varga, S., & Guignon, C. (2020, March 21). *Authenticity*. Stanford Encyclopedia of Philosophy.

planning for the series of events required for an action to occur. It must also correspond to the agent's conception of the action even if a planned action does not happen as intended. For example, an individual who has planned out every step to travel abroad may not achieve their desired outcome but is still acting with intentionality. In other words, the consequences of a planned action and the control the agent has on the consequences have no effect on the intentionality of that action. An individual may have no control over the outcome of their actions, for example, playing the lottery. As long as there is planning behind an action, it is intentional.⁷⁹ The opposite of an intentional action is an unintended action that is executed with no planning, such as accidentally injuring oneself. Per the Beauchamp and Childress description of autonomy, this action would be nonautonomous. Now, intentionality has been established as a principle of planning, but how is this planning done and why is acting with intentionality important? To plan for an action, one must appeal to their attitudes: beliefs, intentions, desires in the hope of achieving their intended consequences. 80 Even if the current attitude or desire of a patient is to act against their values, that must be respected as long as their action is performed with planning. A previous example illustrated this: a patient who typically holds curative values may opt to pursue a palliative route to improve their quality of living. In the biomedical setting, acting with intentionality is essential. Ensuring that a patient is truly acting with a plan they have chosen for themselves allows for reaching a decision that

⁷⁹ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104). Oxford University Press.

⁸⁰ Bratman, M. E. (2005). Planning agency, Autonomous Agency. *Personal Autonomy*, 33–57.

best aligns with their wishes. Although the intended consequences may not always be fulfilled, the action is still executed with respect to the patient's goals. This allows for a greater respect of patient autonomy.

The second condition for an autonomous action is *understanding*. Before an individual can plan and perform an action, they must have a sufficient degree of understanding of the action first. Essentially, one must possess a *substantial degree* of knowledge on the elements of an action, the anticipated consequences, and the outcome of acting alternatively prior to acting intentionally. According to Beauchamp and Childress, the sufficiency of the degree of understanding, that is, the cutoff point of relevant understanding required varies between different situations.⁸¹ Different medical cases require different levels of understanding. For example, the amount of understanding needed for minimally invasive procedure such as a suture removal would be less than the level required to consent to brain surgery. Therefore, the level of understanding that is required to act autonomously varies according to the context. What determines the degree of understanding in an individual? For one to plan the series of events for their action to take place, they must first possess a sufficient degree of understanding. In other words, if an individual understands enough about their case, they are able to conceptualize their intended outcome and plan their action accordingly. Conversely, if an individual lacks a substantial level of knowledge, they are unable to act intentionally. This means that the degree of understanding is determined by the ability to act intentionally. Suppose a

⁸¹ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104). Oxford University Press.

patient is prescribed a medication with a side effect of drowsiness by their physician. The patient happens to be a construction worker and tells the physician that this side effect disrupts their work and would like an alternative medication that enables them to work. By doing so, the patient demonstrates enough understanding about the situation to make an intentional decision.

The need for an individual to possess a substantial degree raises an interesting point. Unlike the first condition where an act is either classified as intentional or unintentional with no in-between, *understanding* can present in various degrees. This means that autonomy can also present in various degrees. In other words, understanding can be more or less complete and therefore, the autonomy of an action as well. An individual with a higher extent of understanding would correctly describe the factors determining the nature of an action, foreseeable consequences, and the result of performing or not performing the action. On the other end of the spectrum, an individual with extremely low levels of understanding will not apprehend any of the aspects of an action, deeming that action nonautonomous. 82 Beauchamp and Childress argue that a full degree of understanding is not required as this would limit the scope of autonomous actions. 83 As their conception of autonomy is directed at nonideal conditions to remain realistic and applicable to medicine, a complete degree of understanding – an ideal condition – must not be included. Beauchamp and Childress explain the restriction of acts to those with full understanding as stripping acts of their meaningful place. How can one

⁸² Beauchamp, T. L. (2005). Who deserves autonomy, and whose autonomy deserves respect? *Personal Autonomy*, (pp. 314–315). Cambridge University Press.

⁸³ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104). Oxford University Press.

be expected to know everything relevant to an action prior to acting? For example, if one were to drive to a grocery store without the knowledge of the current state of traffic or the hours of the store, their action would be deemed nonautonomous. To avoid the exclusion of most actions, only a basic level of understanding is required to act autonomously. If one understood the basics of going to a grocery store, the method of travel and an idea on a list of groceries, they would be acting autonomously. Similar to broadening the understanding of *intentionality* to planning, the same is required with the second condition. There are multiple factors that can hinder understanding including illness, irrationality, immaturity, and communication issues. 84 While some patients are attentive and engaged in conversation about their medical decision-making, others are distracted, and this might limit their understanding. Also, the information might be presented in a way that misleads patients. In cases where the patient is unable to adequately process the information presented, their level of understand can be raised so that they can act autonomously. Professionals can explore different communication strategies to overcome this barrier such as drawing analogies and simplifying information. 85 When actions are limited by such factors to the point they are made with a deficient degree of understanding, they become nonautonomous. In the context of healthcare where actions can have direct implications on one's outcome and quality of life, it is crucial that one acts only with a substantial level of understanding, and nothing less.

⁸⁴ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104). Oxford University Press.

⁸⁵ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 129). Oxford University Press.

The third and final condition of an autonomous action presented by Beauchamp and Childress is noncontrol or voluntariness. In addition to acting with intentionality and sufficient understanding, an individual must also act with the freedom of controlling influences that impede their self-directed course of action – internal and external. Internal controlling influences are factors that have a negative intrinsic impact on the individual's ability to make autonomous decisions, such as mental illness, disease, and drug addiction. Beauchamp and Childress focus more on external controlling influences, the influence of one person on another, in the form of coercion, persuasion, and manipulation, but this does not imply that internal factors are any less significant. 86 Coercion, the most obvious form of external influence, is described as the control of a person over another person with the use of a credible threat of harm or controlling force that displaces a person's self-directed course of action. It only occurs when a credible threat has been made and not when the victim *feels* threatened. An example of coercion is a victim being forced to give up a hefty sum of money after a gun was pointed to their head. Persuasion is simply the convincing of a person through the merit of reasons advanced by another person. An example is an advertisement persuading the public to quit smoking. Persuasion does not compromise autonomy to the extent that coercion does.⁸⁷ Like the second condition of autonomy, noncontrol exists as a spectrum. The presence and impact of controlling influences vary, for example, the effect of a mental illness may impede a patient's intentional decision-making ability more than the persuasion of a family member. Similar

⁸⁶ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104). Oxford University Press.

⁸⁷ Beauchamp, T. L. (2005). Who deserves autonomy, and whose autonomy deserves respect? *Personal Autonomy*, (p. 315). Cambridge University Press.

to *understanding*, there is a cutoff point for voluntariness that is dependent on the particular context. In certain situations, especially those associated with more serious risks, a higher level of voluntariness might be needed to assure the patient's action is of their own volition. Suppose a patient in her later stages of pregnancy receives news that continuing her pregnancy poses the risk of her death. Terminating the pregnancy also presents the same risk, but to a lesser extent. The patient comes from a religious background and has family members attempting to strongly persuade her into continuing the pregnancy as they would consider aborting the fetus morally wrong. Due to pressure from her family and conflicting values, the patient is unable to determine her self-directed course of action. In such a case, the physician may ask to speak to the patient alone to determine her independently decided course of action and execute an action accordingly.

There is also dependence on the state of the patient. If the patient exhibits less independence, then a lower degree of voluntariness can be expected. On one end of the noncontrol spectrum is the more serious coercion, and on the other end lies persuasion. In between, there exists manipulation. The main idea behind manipulation is to get a person to do what the manipulator wants without the use of coercion or persuasion. Manipulation limits one's autonomy, but can also deprive them of it, like coercion. This can be done through threat or punishment, but also through the sharing of information. For example, a salesperson influencing a customer to purchase a product by introducing fears of a competitive product is said to be acting with manipulation and limits the customer's ability to make an autonomous choice. On the contrary, manipulation in the form of withholding critical information is said to deprive one's autonomous choice. This is seen

in healthcare when the information the patient receives is managed to alter their understanding and decision-making.⁸⁸ Manipulation in healthcare largely presents in the form of rewards, offers, and encouragement.⁸⁹ Acting with a sufficient degree of voluntariness is essential in making decisions from one's own volition and acting in accordance with self-directedness to reach an outcome the agent desires.

The three conditions of an autonomous action have been presented: *intentionality*, understanding, and noncontrol. To demonstrate how Beauchamp and Childress's autonomy works in healthcare, here is an example. Suppose an adult patient with no significant medical history presents to an Emergency Department following a fall in which they hit their head. They did not lose consciousness, but now have a head wound with significant bleeding. The physician explains that the most reasonable course of action would be to scan the head to assess the injury before suturing the wound and explains the risks of acting otherwise. The patient is presented with all the relevant information necessary to make a decision and exhibits understanding of the situation and the outcomes of the potential actions. Despite this, the patient states that they would like to be discharged with some bandages for the wound so they can get home to their daughter, who needs a caretaker. Would be this be an autonomous choice? This can be determined by applying the three conditions of an autonomous action. The first condition of autonomy is intentionality. Has the patient planned out their action? The patient's intended action is to return to their daughter. When asked about their decision, they

⁸⁸ Beauchamp, T. L. (2005). Who deserves autonomy, and whose autonomy deserves respect? *Personal Autonomy*, (pp. 315-316). Cambridge University Press.

⁸⁹ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 134). Oxford University Press.

explain that a friend can pick them up and drop them off at home so that the patient can attend to their daughter. Since the series of events required for this plan to happen has been thought out and is consistent with the patient's conception of the act, it can be said that the patient is acting with intentionality. The next condition for an act to be autonomous is understanding. Does the patient possess sufficient knowledge to reach their decision and an adequate level of understanding? As mentioned, the patient was presented with all the relevant information pertaining to their case: the nature of the injury, the benefit of scanning the area of injury, the risks of acting otherwise, medications to use, the timeline of the injury, instructions on how to care for the wound and when to return to the hospital. The patient lacks any limitations to understanding such as mental illness or communication barriers. They are also not limited by their current injury. The patient possesses sufficient knowledge on the situation and used their knowledge to make their decision. Therefore, they demonstrate a substantial level of understanding, and meet the first two criteria of an autonomous action. The final condition of autonomy discussed by Beauchamp and Childress is noncontrol. The patient must be acting without the presence of any internal or external controlling influences that affect the patient's self-directed course of action. The patient has no significant medical history and is not affected by their injury and thus, no internal controlling influences exist. As for the external aspect, there are no individuals that attempt to either coerce to manipulate the patient into doing what they want. The physician may have tried to persuade the patient into staying and receiving medical treatment, but since this persuasion had no effect on the patient's self-directed course of action, this does not

affect the autonomy of the action. Due to the lack of control, it can be said that the patient is acting of their own volition. All three conditions of autonomy are met, making their action autonomous. This means the healthcare staff must respect the patient's choice to be discharged.

2.4: The Physician-Patient Relationship and the Emanuel's Four Models

The physician-patient relationship can be traced back to thousands of years ago. In the early days of medicine, the physician was considered the sole technical expert with the patient considered a sick individual in need of medical protection, assumed as a position of decreased autonomy. Due to this, the patient occupied a minor role in their own medical decision-making, described by the traditional *paternalistic model*. This model encapsulates the concept of *paternalism*.

Paternalism originated from the Latin word *pater*, meaning "father" and refers to the patriarchal dynamic of the father who acts as the authoritative figure responsible for the well-being of his family. Like autonomy, paternalism is a concept of well-being, but is opposite in the level of independence. On the scale of independence, autonomy takes position on one end while paternalism is the other extreme. While an autonomous individual can make decisions for their personal needs and wants, an individual subjected to paternalism is unable to use their decision-making ability to increase personal benefit.

⁹⁰ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2221.

⁹¹ Fernández-Ballesteros, R., Sánchez-Izquierdo, M., Olmos, R., Huici, C., Ribera Casado, J. M., & Cruz Jentoft, A. (2019). Paternalism vs. autonomy: Are they alternative types of formal care? *Frontiers in Psychology*, 10.

⁹² Murgic, L., Hébert, P. C., Sovic, S., & Pavlekovic, G. (2015). Paternalism and autonomy: Views of patients and providers in a transitional (post-communist) country. *BMC Medical Ethics*, *16*(1).

Rather, it is the authoritative figure that makes decisions on behalf of the person for that person's well-being. In other words, autonomy enables a mutual relationship between personal needs and rights while paternalism causes a conflict between needs and rights.

The paternalistic dynamic of medicine would constitute an era that lasted millennia, referred to as *The Age of Paternalism*, discussed by Mark Siegler. ⁹³ The authoritative nature of medicine in this era is defended by a utilitarian ethic. A utilitarian is concerned with achieving the most beneficial consequences. In this context, that would be the well-being of the patient. The argument was "doctor knows best" and so to reach the best possible outcome, the doctor should have full control of the situation. The end of this era was brought about in the mid-twentieth century by rapid advances in medical technology and a greater understanding of the human body. This marked a new era, deemed *The Age of Autonomy* by Siegler, which saw the rise of antipaternalism. The argument against paternalism arose mainly against the assumption that the physician knows what is best for the patient. This resulted in greater patient respect, namely in the form of informed consent: disclosure of complete, unbiased information pertaining to a patient's situation allowing them to make an independent decision. 94 Proponents for patient autonomy argue that paternalism caused a divide between the patient's autonomy and the physician's role which has undermined the mutuality between the physician and the patient. The divisive landscape of the physician doing something to the patient rather

⁹³ Siegler, M. (1985). Who Should Decide?: Paternalism in Health Care, by James F. Childress. *Perspectives In Biology And Medicine*, 28(3), 452-456.

⁹⁴ Kumar, N. (2013). Informed consent: Past and present. *Perspectives In Clinical Research*, 4(1), 21.

than with the patient created a harmful reflection of healthcare. ⁹⁵ This new era introduced a crucial question: what is the ideal allocation of decision-making power?

In 1992, Ezekiel J. Emanuel and Linda L. Emanuel aimed to answer this question by proposing four models of physician-patient relationships with emphasis on the ideal model. It is important to note that Emanuel and Emanuel's four models do not act as a legal standard, but rather describe ethical ideals. They list four fundamental features of physician-patient relationships with an explanation of each feature for each model: (1) the understanding of the patient's autonomy (2) the patient's values, (3) the physician's duties, and (4) the goals of the physician-patient relationship. ⁹⁶ Before detailing these characteristics, I will briefly describe the four models.

The first model of physician-patient relationships is the *paternalistic model*. It is termed "paternalistic" because the physician takes the role of the patient's guardian in medical decision-making with the assumption of shared moral values. The physician uses their skills to determine the patient's medical condition and select a treatment plan they consider best. This is done independently of the patient's wishes. The patient is presented with information and is encouraged to consent to the plan chosen by the physician. The paternalistic model assumes there are shared objective criteria in determining the best decision, allowing for limited patient involvement. This model assumes that the patient will be thankful for the physician's decisions, even if there is an initial disagreement. The paternalistic model highly prioritizes the patient's well-being over their decision-making

⁹⁵ Koppelman-White, E. (2009). The Search for Reasons in a Unified Relationship. *Journal Of Medicine And Philosophy*, *34*(5), 447-469.

⁹⁶ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2221.

ability.⁹⁷ The paternalistic model is widely considered justifiable only under emergency circumstances where waiting for informed consent would harm the patient. With all the decision-making power in the hands of the physician, it is clear there is a lack of respect for patient autonomy.

The second model is the *informative model*. Here, the physician acts as an informant, providing the patient with details relating to their condition and treatment such as the nature of the risks, benefits, and outcomes. The patient then participates in medical decision-making by analyzing the facts disclosed by the physician. The values of the patient are already established in this model and are used in determining the preferred course of action. The physician executes the patient's selected plan.⁹⁸

The third model is the *interpretive model*. Like the informative model, the interpretive model sees the physician providing relevant information to the patient regarding their medical case – the nature of the risks, benefits. The difference is the patient's values are typically preliminary and conflicting, requiring elucidation. The physician acts as an advisor instead of an informant by conversing with the patient to help them understand their moral values. This is achieved through reconstructing the patient's goals and character. The physician helps the patient in making a medical decision that best aligns with the patient's values. Ultimately, the patient reaches the decision which the physician implements.⁹⁹

⁹⁷ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2221.

⁹⁸ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2221.

⁹⁹ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2222.

The fourth and last model is the *deliberative model*. Assuming the role of a friend or teacher, the physician engages in moral deliberation with the patient to compare health-related values and help them in determining which values to pursue. The physician is responsible for providing relevant information and helping the patient in understanding this information, particularly the health-related values represented by the available options. They also provide suggestions on which values to pursue. The physician shares their preferred course of action, but ultimately, it is left to the patient to choose the health-related values they deem fit and making a medical decision that promotes those values. This is supported and implemented by the physician.¹⁰⁰

To highlight the differences between each model, Emanuel and Emanuel present a medical case and how this case would be handled under the four models. A woman has been recently diagnosed with an operable breast mass with no evidence of metastasis after imaging and lab tests. How would a paternalistic, informative, interpretive, and deliberative physician approach this case? A paternalistic physician may approach the patient and explain that there are a few alternative therapies to protect against recurrence of breast cancer. Then, they might say, "A lumpectomy combined with radiation is the preferable route because it would offer the best survival and cosmetic result, so I have contacted the radiation therapist to discuss the treatment with you. Additionally, recent studies show that chemotherapy would increase the chances of survival. The next few months will be difficult, but worth the decreased risk of breast cancer reappearing."

¹⁰⁰ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2222.

The informative physician may approach the case in such a manner, "There are two issues here – local control and systemic control. With local control, mastectomy and lumpectomy combined with radiation both result in an eighty percent survival rate over ten years. Alternatively, lumpectomy without radiation results in a thirty to forty percent chance of tumor recurrence. With systemic control, recent studies have shown that chemotherapy can have a positive therapeutic effect but has no benefit for overall survival. There are clinical trials to evaluate the benefits of chemotherapy for patients with the same type of cancer. I can enroll you in such a trial."

When it comes to the interpretive physician, they would present much of the same information as the informative physician, but then would participate in discussion with the patient to clarify the patient's wishes. Since the interpretive patient has conflicting wishes, the physician might respond, "You have conflicting wishes and are unsure how to balance the complexities of treatment with your personal life and mental well-being.

Allow me to explain the treatment options and their implications on your personal life. Of course, treating your cancer is important but the negative impact on the quality of your life must be minimized. As such, it seems that this is best achieved with radiation therapy but not chemotherapy. A lumpectomy with radiation maximizes the chances of survival while preserving your breast. Radiation therapy battles the cancer without any cosmetic changes. Chemotherapy would prolong the treatment duration by many months for a smaller and controversial benefit. It seems to maintain your quality of life; chemotherapy is not the preferred option."

Lastly, the deliberative physician would present the information and engage in a discussion to clarify the patient's values like the interpretive physician. However, they would continue, "Radiation therapy appears to be the most suitable option – maximal survival, minimal risk, and a lower detriment on the quality of your life. Additionally, I think that pursuing a chemotherapy trial would be preferable. Not only does it ensure that you receive great medical care, but it is altruistic. This is an opportunity to contribute to important research and participate in something that will benefit the future of women." 101

It is important to note that Emanuel and Emanuel prefer the deliberative model for physician-patient relationships. They explicitly state, "Descriptively and prescriptively, we claim that the ideal physician-patient relationship is the deliberative model." They offer an explanation in terms of autonomy to defend their claim. They say that the deliberative model embodies their ideal of autonomy: "Freedom and control over medical decisions alone do not constitute patient autonomy. Autonomy requires that individuals critically assess their own values and preferences; determine whether they are desirable; affirm, upon reflection, these values as ones that should justify their own actions; and then be free to initiate action to realize the values." The moral deliberation of the deliberative model allows for autonomy to be understood this way.

¹⁰¹ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2222-2223.

¹⁰² Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2225.

¹⁰³ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2225.

2.5 Features of the Models

Below I discuss the essential characteristics that define and differentiate the physician-patient interaction in each of the four models, as detailed by Emanuel and Emanuel.

2.5.1: The Concept of Patient's Autonomy: Decision-making and Values

The first feature of the models is the understanding of the patient's autonomy. In the field of biomedical ethics, the definition of autonomy introduced by Beauchamp and Childress is used. They presented three conditions for autonomy: intentionality, understanding, and noncontrol. ¹⁰⁴ In the paternalistic model, the patient and physician share the same moral values, making these values established in decision-making. The patient is expected to consent to the physician's selected plan that was chosen to fit the shared values. Typically, the patient understands the information pertaining to their case that is presented to them by the physician. Since the patient displays a sufficient degree of understanding, they are able to act intentionally. Although the patient does not participate in the decision-making, and merely processes information, they are intentionally assenting to the physician. With the third condition of autonomy, the patient is not subjected to persuasion at the least and manipulation at the extreme. Here, manipulation would take the form of withholding of information. In the case of the paternalistic model,

¹⁰⁴ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104).
Oxford University Press.

the patient fails to meet the third condition of autonomy – noncontrol – and therefore, considered not fully autonomous.

A physician in the informative model is providing and explaining information to the patient regarding their medical condition, treatment, and outcome. The patient uses their established moral values to analyze this information and reach a decision that best aligns with their wants. The physician helps in explaining this information to the patient. It can be said that a patient acting under the informative model possesses an adequate degree of understanding of the relevant information of their medical case. Using their knowledge, they make an intentional decision. Since the physician does not participate in the decision-making, the patient has full control over medical decision-making with no controlling influences. The informative patient is acting with intentionality, understanding, and noncontrol. Therefore, this patient possesses autonomy.

In the interpretive model, the patient is presented with the relevant information with the physician offering explanations. The values of the patient are not defined. Through clarification of their moral values by the physician and the use of medical information, the patient reaches a decision matching the values they have chosen to follow. Like the informative model, the patient is enabled to plan their action using the information presented to them and acts intentionally. The patient experiences self-understanding as they better understand their values with the help of the physician. ¹⁰⁶ There is no difference in the interpretive patient's understanding of the situation. They

¹⁰⁵ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2221.

¹⁰⁶ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2222.

obtain sufficient knowledge through the physician. Similar to the informative model, the patient has full control over the decision-making. Since they fulfill all three conditions, they are autonomous.

Lastly, the physician and patient in the deliberative model engage in moral discussion to judge the merits of health-related values. The physician offers suggestions on which values to pursue. Ultimately, it is the patient that selects the values they want to follow and chooses an action that embodies those values. Like the informative and interpretive model, the deliberative model allows the patient to formularize a plan with respect to their intentionality. The physician conveys and explains the pertinent information so that the patient develops an adequate level of understanding. At the most, the patient is influenced by moral persuasion, but not to the extent that it comprises autonomy. They are still capable of achieving their self-directed course of action. The deliberative patient meets all three conditions of autonomy and is therefore, autonomous.

2.5.2: The Physician's Duties

Each model has its own definition of the physician's obligations. As mentioned, a physician operating under the paternalistic model acts as the patient's guardian by making decisions for them. By determining the best plan independent of the nonautonomous patient, the physician's role is seen as promoting the patient's health over their ability to make decisions.

¹⁰⁷ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2222.

With the informative model, the patient makes a medical decision using their own moral values, but with the help of the physician's information. Here, the physician's duties are to show competency in their field by providing the patient with factual and truthful information that enables them to make an independent decision. Then, the physician implements the patient's decision. They are also obligated to consult others when their knowledge is insufficient. ¹⁰⁸

The physician's role in the interpretive model is similar to a counselor and has another duty than the informative physician. A physician is expected to provide unbiased information that helps the patient in reaching a decision but is also responsible for guiding the patient in realizing their moral values through explanation and applying them to the medical situation before implementing the patient's choice.

Lastly, the physician's duties in the deliberative model are considered most significant. Besides providing medical information to the patient, the physician also immerses themselves in moral discussion with the patient. Through moral conversation, the physician persuades the patient of the most admirable values. Following deliberation, the patient arrives at a decision that is executed by the physician.

2.5.3: The Goals of the Physician-Patient Relationship

Finally, what is hoped to be accomplished with a physician-patient interaction? With the definition of the previous features, this can be answered. As mentioned, a

¹⁰⁸ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2221.

physician serving under the paternalistic model acts as the patient's guardian by making decisions for them. Therefore, the goal of the paternalistic model is to follow the best course of action determined by the physician with the prioritization of the patient's health over their own autonomy.

The informative model sees the physician acting as a competent technician by providing facts to the patient. Such facts may include the current condition of the patient, a prognosis, and the risks and benefits of different treatments. Following the relay of information, the patient makes their own decision which the physician enacts. Therefore, the goal of the informative model is for an independent determination of a preferred plan by the patient using their own established moral values and facts delivered by the physician to promote their well-being.

In the interpretive model, the physician provides objective information on the medical status of the patient just like the informative model. However, the physician acts as an advisor by helping the patient in determining and understanding their moral values which are then used by the physician and patient to make a medical decision. The physician suggests medical interventions that best align with the patient's values, but again, the decision is ultimately made by the patient. Therefore, the goal of this type of interaction involves a patient reaching a medical decision with the use of objective information and their moral values which are fully understood with the help of the physician.

Finally, a physician and patient, acting under the deliberative model – both considered autonomous – are seen engaging in moral deliberation. Here, the physician

not only provides medical information but discusses the most commendable values. With moral guidance from the physician, the patient makes their final decision. To conclude, it can be said the goal of the deliberative physician-patient interaction is for the patient to reach a decision through moral deliberation with the physician.

CHAPTER 3: A MODEL FOR ORGAN PROCUREMENT

3.1: Introduction

The first two chapters explained two separate concepts. The first discussed the subject of organ procurement: what constitutes the process, the lengthy history and the ethical issues surrounding the practice. In particular, the three definitions of death — heart-lung death, whole brain death and higher brain death — in accordance with the dead donor rule (DDR) along with the national organ shortage were explained. The second chapter initially analyzed the concept of autonomy: moral autonomy, personal autonomy and Beauchamp and Childress' biomedical autonomy. After explaining the three conditions required for an action or decision to be autonomous in a biomedical context, the chapter moved on to the four models of physician-patient relationships proposed by Emanuel and Emanuel. The models were explained in relation to these three conditions of biomedical autonomy: intentionality, understanding and noncontrol.

Organ procurement – the surgical removal of a viable organ from a donor for reuse in a recipient's body – is only possible after consent is obtained from the family of the potential donor. ¹⁰⁹ Acquiring consent can only be achieved through a difficult conversation with the family. In cases where the patient has explicitly stated their desire for organ donation, the process of procuring organs is relatively straightforward. However, in cases where the patient has not indicated their status on organ donation, the

¹⁰⁹ U.S. National Library of Medicine. (n.d.). *Tissue and organ harvesting - mesh - NCBI*. National Center for Biotechnology Information. https://www.ncbi.nlm.nih.gov/mesh/68020858

physician or healthcare professional is responsible for facilitating this sensitive conversation with the family along with the organ procurement organization (OPO) staff. What makes this conversation difficult? Prior to organ procurement, the classification of death must be declared by the physician. This entails explanation of the categories of death and the organs that can be procured as a result of the type of death that occurs before the family can make a decision. For instance, an individual who is brain dead but still has active cardiopulmonary functioning can donate their heart, liver, pancreas, eyes/corneas, kidneys, intestine, heart valves, skin, bone, and lungs. Alternatively, an individual falling under the classification of heart-lung death can only donate their eyes/corneas, blood vessels, cartilage, skin, bone, pericardium, and soft tissues. ¹¹⁰ From the perspective of a grieving family who likely lacks a medical background, a discussion surrounding the complexities of death for the purpose of their loved one's organs may not be welcomed. Furthermore, such complexities may not be understood by the family.

What can be done to combat the difficulties of the criteria of death conversation? This brings us back to the four models of physician-patient relationships outlined by Emanuel and Emanuel. While their models describe the relationship between a physician and patient, they can be applied to the relationship between a physician and patient's family. Additionally, the purpose of the four models is to enable decision-making for the benefit of the patient, but when applied to the organ procurement conversation, the

¹¹⁰ Understanding the organ/tissue procurement process. National Kidney Foundation. (2014, August 12). https://www.kidney.org/news/newsroom/fs_new/organ%26tissueprocprocess

purpose is to empower the decision-making of the family not to benefit the patient, but an anonymous third party. Emanuel and Emanuel clearly state that the fourth model – the deliberative model – is the ideal model for physician-patient relationships. However, what is the best model for the organ procurement conversation? Also, can any of the models adequately approach the complications of such a sensitive conversation? Before the four models can be applied to organ procurement and these questions can be answered, the autonomy of the loved ones of a potential organ donor must be analyzed.

3.2: The Family's Autonomy

Understanding where the family lies in terms of autonomy allows us to determine the precise relationship between the physician and the family. As discussed previously, the Beauchamp and Childress definition of autonomy highlights three conditions for an action to be autonomous and focuses on the capability to make autonomous decisions. Since the organ procurement conversation is biomedical in nature, their conditions can be used to evaluate the family's autonomy.

The conditions of autonomy are *intentionality, understanding*, and *noncontrol*. I will first discuss the third condition – noncontrol or voluntariness – because I argue that this condition affects the previous two. For an individual to be acting with voluntariness, they must act with the freedom of controlling influences that impede their self-directed

course of action – internal and external. 111 In the case of a family being approached for a conversation of procuring their loved one's organs, the action or rather, decision would be whether to consent to organ donation. What constraints are present in this situation? Firstly, the internal constraints affecting decision-making are the emotions involved in grieving. A family has received news on their loved one's death and has begun the grieving process. Shortly afterwards, a conversation about organ procurement is initiated by the relevant organ procurement organization, with further information supplied by the physician as necessary. How can the family be expected to act in accordance with their self-directed course of action? In many cases, their emotions would disrupt their selfdirectedness. Next, the external constraints discussed by Beauchamp and Childress that affect autonomy are coercion and manipulation. 112 The family may very well be coerced or manipulated into consenting to organ donation. However, this is dependent on the dynamic between the physician and family and is explained when discussing the different dynamics in relation to organ procurement. Although, Beauchamp and Childress place more emphasis on external constraints, the internal controlling influences are more prevalent.

The second condition of autonomy is *understanding*. For an action to be autonomous, it must be done with a sufficient level of understanding of the action.

Essentially, one must possess a *substantial degree* of knowledge on the elements of an action, the anticipated consequences, and the outcome of acting alternatively prior to

¹¹¹ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104). Oxford University Press.

Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104). Oxford University Press.

acting *intentionally* – the first condition of autonomy.¹¹³ The knowledge required to adequately understand organ procurement – namely, the type of death and organs that are viable – is relatively complicated, but especially difficult when internal constraints are present. In other words, how can the family of a deceased individual be expected to understand the intricacies of death and the complicated process of organ procurement when they are actively grieving the loss of their loved one? Both the internal constraints and understanding exist in levels. At the maximum, the emotions of the family are so intense that they are unable to adequately understand the information presented to them. The degree of internal controlling influences directly affects the level of understanding which in turn affects the intentionality of the action.

Intentionality is defined in terms of planning. Beauchamp and Childress state that for an action to be intentional, it must be done with planning for the series of events required for that action to occur. 114 If a family lacks a sufficient level of understanding due to internal constraints, then they are unable to act intentionally. This is because acting with intention necessitates an adequate degree of understanding. In conclusion, the presence of internal controlling influences caused by the death of a loved one results in the likely incapability to understand the information of the situation and therefore, the incapability to act intentionally. It can be said that the ability of the family to make autonomous decisions in the setting of organ procurement is either decreased or absent.

¹¹³ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104). Oxford University Press.

¹¹⁴ Beauchamp, T. L., & Childress, J. F. (2019). Respect for Autonomy. In *Principles of Biomedical Ethics*. (p. 104). Oxford University Press.

3.3: Applying the Models

Now that the question of the family's autonomy has been addressed, how do Emanuel and Emanuel's four models apply to the difficult conversation surrounding the criteria of death in cases of organ procurement? In other words, can any of the models both: (1) amend the deficiencies in the autonomy experienced by the family to the extent that they adequately understand the medical concept of death so that an intentional decision can be made, and (2) facilitate autonomous decision-making on the part of the family? As mentioned, a conversation about the criteria of death must be had before the family can even make a decision. It is crucial to note that the application of the four models to organ procurement is a deviation from how these models are typically applied. While Emanuel and Emanuel designed their models to pertain to physician-patient relationships to benefit the patient, this section will apply the four models to a physician-family relationship to benefit an anonymous third party.

To illustrate how a paternalistic, informative, interpretive, and deliberative dynamic would appear in the setting of organ procurement, I will present an example of a medical case and apply each model to the case. A twenty-year-old male is involved in a devastating car accident, leaving him in critical condition. Shortly after arrival in the Emergency Department, the patient is found to have suffered irreversible cessation of all brain stem functions, but still has active cardiopulmonary functioning. Per the American Academy of Neurology (AAN), this patient meets the criteria for brain death as discussed

in Chapter 1.¹¹⁵ The active cardiopulmonary functioning of the patient allows for the extraction of organs with maximized viability due to less ischemic injury. Since the patient is eligible for organ donation, the organ procurement staff is contacted and approaches the family to discuss donation. The family is still in shock over the circumstances of their loved one and now is confronted by a stranger asking for the organs of their family member. The actively grieving family is unsure on how to respond to the exchange with the organ procurement staff member. They look to the physician whom they know and trust for guidance on understanding the situation and how to act. How would a physician acting under each of the four models approach this difficult conversation with the family?

Starting with the physician acting under the *paternalistic model*, they might say, "Unfortunately, the injuries your loved one has sustained are so severe that he has suffered irreversible brain damage. His brain function is no longer active. There are two categories of death: cardiac death and brain death. Cardiac death is caused by stoppage of the heart. Clearly, he does not meet this definition. However, your loved meets the criteria for brain death as his brain is no longer functioning but his heart and lungs are still working. For the purpose of organ donation, brain death is more suitable over cardiac death because there is still blood flow to his organs, making them usable for transplantation. There are many individuals whose lives can be saved with these organs, but they will not be viable for much longer. So, I have talked with the organ procurement

¹¹⁵ Chatterjee, K., Rady, M., Verheijde, J., & Butterfield, R. (2021). A Framework for Revisiting Brain Death: Evaluating Awareness and Attitudes Toward the Neuroscientific and Ethical Debate Around the American Academy of Neurology Brain Death Criteria. *Journal of Intensive Care Medicine*, 36(10), 1149-1166.

staff to initiate the process of organ extraction for future transplantation." Here, the physician is seen making decisions on behalf of the family without incorporating their wishes. This is because the paternalistic model assumes that the family has diminished autonomy and is unable to act autonomously. It also assumes the decision made by the physician is what the family would want if they could act autonomously. It was earlier determined that the family's autonomy in this medical case is either decreased or absent. They are unable to make an autonomous decision because of their internal constraints. Since the family is not involved in the decision-making process at all, they do not even have the opportunity to act intentionally. Rather, the family's role is to assent to the physician's decision. When explaining the criteria of death to the family, the physician boosts the family's understanding, but not to the degree where the family can independently make a decision. Nothing is done to relieve the internal constraints experienced by the family. Rather, the family could be coerced or manipulated into consenting, depending on the severity of the paternalism exercised by the physician. Therefore, the family's deficits in all three conditions – intentionality, understanding, and noncontrol, are not alleviated enough to enable the family's ability to make an autonomous decision. Emanuel and Emanuel note that the paternalistic model is inapplicable beyond limited circumstances. Such circumstances include time-sensitive emergency situations where waiting to obtain consent could harm the patient. In this case, an anonymous third party is not harmed, but is unable to be benefited if the decision to

donate is protracted. ¹¹⁶ A great example of a time-sensitive emergency situation is the current medical case. The patient suffered irreversible loss of brain function and has viable organs but only for a short amount of time. As such, I believe that the paternalistic model can apply to the conversation about death in the context organ procurement, but only in cases where the family is so distressed that they are unable to make an autonomous decision. This being said, the paternalistic model which is typically used to benefit a patient incapable of making an autonomous decision for themselves, fails to uphold the family's autonomy in order to benefit an unknown individual in the setting of organ procurement. The application of this model could make the family feel better that something good came out of the tragedy.

A physician acting in keeping with the *informative model* would explain, "The accident was serious. Your loved one has sustained severe brain injury to the point where his brain is no longer functioning. Unfortunately, the brain damage is irreversible, and the brain function cannot be restored. His heart and lungs are still working, but since his brain is no longer working, it is only a matter of time before his heart and lungs stop too. He meets the criteria for brain death which is caused by irreversibility of brain stem function. Brain death still sees active cardiopulmonary functioning. The other type of death is cardiac death which is caused by the stoppage of the heart and blood flow. When it comes to organ donation, organs are only viable when there is active blood flow. This is only the case with brain death. Since there is still cardiopulmonary functioning, your

¹¹⁶ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2224.

loved one's organs are usable for transplantation for other patients. The organs that are obtained could potentially save numerous lives. The alternative option is to not extract his organs and let them remain intact. If the decision is made to donate his organs, we must act quickly because soon, the organs will no longer be viable. I am happy to provide any further information if needed." The physician provides the family with relevant, objective information that allows the family to reach a decision. Here, the second condition of autonomy is targeted – understanding. Through explanation of the pertinent information, the family's degree of knowledge may be raised. A sufficient degree of knowledge would enable intentional decision-making. It is important to note that in the informative model, the patient's values, for example that he would have wanted to be an organ donor, are known and understood to the family. These values are used collectively with the medical information provided by the physician to decide on a course of action. Therefore, the family is in a position to make the decision that the patient would if he was capable. This is known as substituted judgement and is a guide for decision-making when the patient lacks decision-making ability. 117 Since the informative model centers around the explanation of information, it assumes that the only aspect of autonomy that should be targeted is understanding. The family's understanding is boosted by this model and perhaps their autonomy is elevated, assuming concerns of intentionality and noncontrol are addressed. However, it was previous mentioned that the internal controlling

¹¹⁷ Torke, A. M., Alexander, G. C., & Lantos, J. (2008). Substituted judgment: The limitations of autonomy in surrogate decision making. *Journal of General Internal Medicine*, 23(9), 1514–1517. https://doi.org/10.1007/s11606-008-0688-8

It is important to note that this noncontrol is only internal as no external constraints, such as threats, are being imposed in the informative model. This application of the informative model seems to be narrow as it assumes that only the family's understanding needs to be targeted. Therefore, only in cases where the family's understanding is the sole aspect that needs to be addressed, the informative model is applicable.

In Emanuel and Emanuel's *interpretive model*, it is important to note that the patient's values are unknown or conflicting. In this scenario, it would be the family's values that are unknown or conflicting. The interpretive physician would explain much of the same information as the informative physician, but then would proceed with discussion to clarify the family's values. For example, "It appears that there are conflicting wishes. Although your loved one meets the conditions for death, specifically brain death, their heart is still beating. If the decision to proceed with organ donation were to be made, then you would have to say goodbye while his heart is still beating.

Also, he will be continued to be supported by medical machinery to keep his organs viable for donation. However, if the decision were to not proceed with organ donation, then it would be possible to say goodbye to him after his heart has stopped and he is free of medical equipment. Organ donation is important, but what's more important is what *you need* to say goodbye to your loved one. In medical terms he is dead, but since his heart is still beating it may feel wrong to say goodbye at this stage. Doing so could result

in a lack of closure but would a numerous amount of lives can be saved or significantly improved. Saying goodbye after his heart stops beating while he is not hooked up to machines, may allow the best closure possible. This may be important for your mental well-being, but the opportunity to save lives is dropped. Instead, his organs will no longer be viable for transplantation. I know this is a difficult decision, but I hope this perspective helps." Through explanation of how the family's values are expressed in this situation, the family can act on behalf of the patient. Unlike the informative model which focuses on the understanding of clinical information, the interpretive model focuses on respecting the family's values in terms of what they need to part ways with the patient. In other words, while the family under the informative model performs a substituted judgement using their already known values and the medical information presented to them, the interpretive model analyzes the family's internal feelings to enable decision-making. Notice that this model helps to facilitate understanding, but understanding of a different sort. If the family is able to understand their internal constraints to a sufficient level, then they can act intentionally. The further explanation that a physician acting under the interpretive model offers boosts the ability of the family to make intentional decisions. The interpretive model assumes that the medical understanding of the family is already sufficient, so it is the internal influences that should be targeted – sadness, anger, or grief. However, how can the family be expected to have adequate understanding when they are emotionally distraught?

While understanding can be boosted through a physician explaining information – a task they are accustomed to – the explanation of values in relation to the medical case is

more difficult. This is because physicians may not be used to explaining, or exploring, a family's values. The interpretive model raises an interesting point. Certain aspects of autonomy are more easily elevated than others. Alleviation of internal constraints is not as straightforward as promoting medical understanding. A second point can be made here about the nature of the constraints under which the family is laboring: no external constraints are being imposed in this model. A shortcoming of this model is the assumption of full medical understanding which cannot be true in every case, but the other shortcoming is the assumption that the physician can help the family understand their values. As mentioned, physicians are not adequately trained with having such conversations with families. It cannot be assumed that all physicians can achieve this task. Since in ethics "ought implies can", if physicians are incapable of having this type of conversation, it follows that they aren't obligated to do so. In cases where the family is unclear of their values, where the physician is able to help the family in understanding those values, and where the family's understanding of the circumstances of their loved one is sufficient, the interpretive model is applicable. But such cases seem like the exception, as stated above.

Lastly, how would a physician acting in accordance with the *deliberative model* converse with the family? They would act similarly to the interpretive physician by explaining the relevant information and clarifying the family's values but then would engage in moral deliberation. For instance, "I believe the way to proceed is by prioritizing what is needed to say goodbye. This will allow for the best possible closure and mental well-being. If you are satisfied with saying goodbye while your loved one's

heart is still beating and is still being worked on by the medical team, then I suggest proceeding with organ donation. This option is altruistic and allows patients desperately in need of a new organ to be rescued and contributes to the disparity between organs needed and organs available for donation. If the preference of when to say goodbye does not align with donating organs, you were still able to achieve the best closure possible which is more important. Let's discuss which of these options is the right one for your family." The deliberative physician works with the family to reach a shared decision.

Since the physician provides the family with the relevant medical information and explains the relation between values and decisions, the family's understanding and intentionality are elevated in the same way as in the interpretive model. Also, the analysis of internal feelings is seen as in the previous model.

Although it may seem like the physician and patient are meeting in the middle, the final decision reached using the deliberative model may be what the physician wanted all along. This can be achieved through moral persuasion. After all, the physician may be seen as a moral authority, and isn't operating under the same internal constraints of sadness and grief that are affecting the family. In light of this persuasion, external constraints affecting autonomy may be introduced in the deliberative model. A further drawback of this model when applied to organ procurement is the assumption that the family is even capable of engaging in moral deliberation. How can this be assumed when the family is internally distressed? Therefore, only in cases where the family is capable of and in need of engaging in moral deliberation to reach a shared decision does the deliberative model apply.

3.4. Conclusion

Emanuel and Emanuel's four models of physician-patient relationships were applied to the conversation of the death of a potential organ donor between the physician and family. This conversation is necessary to enable the family's decision making to benefit an anonymous third party. This irregular application of the four models was done to answer the question: Which model best applies to the "death for organ donation" conversation?

As discussed in the previous chapter, Emanuel and Emanuel clearly state that their ideal model is the deliberative model, "Descriptively and prescriptively, we claim that the ideal physician-patient relationship is the deliberative model." When it comes to the conversation of death and organ donation, there is diversity in the family's intentionality, understanding and noncontrol. Not every family will show the same level of the three aspects of autonomy. Each of the models aims to enable decision making of the family in different ways. The models also have different assumptions of the family that results in applicability only when those assumptions are true. For example, the informative model assumes that only understanding needs to be addressed while the interpretive model assumes that the level of understanding is already adequate. The result of this and the answer to the aforementioned question is this: There is no model that is necessarily more applicable than the other. Rather, the model that is most applicable is

¹¹⁸ Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA: The Journal of the American Medical Association*, 267(16), 2225.

dependent on the family. More specifically, it is dependent on the family's intentionality, levels of understanding, and controlling influences. Certain models are applicable in certain situations. It all comes down to whom the physician is approaching. It is interesting to note that the conclusion that there is no ideal model is a deviation from what Emanuel and Emanuel clearly state – the deliberative model is the ideal model.

The process of organ procurement in the United States has been ethically troubled since its start in the 20th century. A major ethical problem of procuring organs is a lack of respect of autonomy for the deceased patient and their family. To combat this issue, this thesis discussed the ethical history of organ procurement before elaborately explaining the definition of autonomy in bioethics. Beauchamp and Childress's three-pronged definition of autonomy was introduced and related to Emanuel and Emanuel's four models of physician-patient relationships. The four models were applied to the first step of organ procurement: a conversation between the physician and the patient's family about the circumstances of the patient's death. Only after this conversation can the process of organ donation proceed. The application of Emanuel and Emanuel's models found that there is no one model that is the most applicable for the organ procurement conversation. Rather, the model that is applicable depends on whom the physician is conversing with.

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