CASE STUDY

Applied ethics in health care administration: A case study of organ donation in an unidentified person

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ABSTRACT

Ethical leadership in health care helps to guide the administrator through difficult decisions, upholding the policy of the institution while putting patient care first. This case study presents an ethical dilemma encountered by the administrator regarding organ procurement in an unidentified person who dies within the hospital. The purpose of this report is to provide a comprehensive literature and concept review of the bioethical considerations of organ donation in an unidentified person, to review the current status of the Uniform Anatomical Gift Act (UAGA), and to provide a review of presumed versus informed consent. These are all aspects that shape ethical decision-making for the health care administrator. Forty-eight states have adopted UAGA legislation governing regulations regarding organ donation. In states where the legislation has been enacted, the authority to consent for organ donation is granted to the custodian of the body. In the case of persons who are unidentified, individual state regulations often grant custodianship to the hospital in which the patient died. Health care administrators may be called upon to consent for hospital procedures in cases of diminished capacity and the absence of a substitute decision maker. The health care administrator needs to be well-informed about the ethical framework for decision making in order to opine regarding organ procurement based on patient autonomy and uphold the current laws and hospital policy with beneficence and integrity.

Key Words: Bioethics, Autonomy, Organ donation, Organ donor, Uniform Anatomical Gift Act

1. CASE AND BIOETHICAL CHALLENGE

An elderly black female was found slumped over a bench at a bus station in New Jersey and paramedics were called. She was found to have cardiac rhythm abnormalities and was immediately transferred to the local hospital emergency department (ED). In the ED, she was found to have profound neurologic deficits and two large areas of ischemic stroke, with associated brain edema on CT scan. She was subsequently intubated, placed on a ventilator, and immediately transferred from the local hospital to the area's tertiary medical center intensive care unit (ICU) for further management. Attempts were made to identify the patient with police assistance, without success.

In the tertiary care hospital, a repeat scan of the brain noted extension of the stroke with poor prognostic indicators, including additional areas of damage and worsening brain edema causing a high potential for brainstem herniation. The patient remained unidentified in the ICU and area police were called who performed fingerprint analysis and entered her picture into facial recognition software. No return identification was made despite aggressive measures. The patient was noted to decline clinically with loss of further neurologic responses. A bioethics consultation was called for consideration of de-escalation of aggressive measures in the setting of

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a very poor prognosis.

The patient subsequently began to decline rapidly and she was declared brain dead by radiographic and clinical criteria in accordance with hospital policy. Also in accordance with hospital policy, the patient's death was reported to the organ donation organization associated with the institution. The organ donation organization personnel informed the ICU staff that an unidentified person who is declared brain dead was directed toward organ donation. Further, the hospital administrator was informed that she was obliged to sign the consent providing there was no evidence that the patient would not want organ harvesting.

2. DISCUSSION

Transplantation medicine is an area that has created unique bioethical challenges. Organs from transplanted patients can be harvested after cardiac death or confirmed brain death. While a discussion of the technical aspects of organ procurement in this setting is beyond the scope of this article, it should be noted that brain dead donors are the primary source of most viable organs for donation. The cornerstone concept of transplant ethics is the "dead donor rule" in that the donor of the organs is not killed by the act of organ removal.^[1] Recent highly publicized controversial cases have arisen regarding the public acceptance of brain death as a diagnosis, though experts contend that the science behind brain death is irrefutable.^[2]

This particular case brings up the concept of organ donation using a surrogate decision maker - one who knows nothing of the patient, her wishes, or her life philosophy. The patient's attending physician experienced moral distress, as her perception was that the autonomy of the patient was not a primary consideration, and the organ donation decision was being made as a matter of policy. Institutional policy often reflects legal precedent and is approved by the bioethics committee of the institution. Therefore, although clinicians are perhaps most strongly influenced by either societal or personal beliefs, a discussion of pertinent law is essential when making difficult decisions. This also necessitates a review of what constitutes presumed consent and how it differs from informed consent, as the difference between these two illustrates an important difference between organ donation in the United States and much of Europe.^[3]

Additionally, physicians facing difficult cases like this rely on a complicated and somewhat controversial set of medical ethics. Ever since Tom Beauchamp and James Childress introduced the principles of autonomy, beneficence, non-maleficence, and distributive justice in their Principles of Biomedical Ethics in 1979, these long-accepted tenets have driven much of American bioethical decision-making.^[4] However, some of their implications and related concepts have more recently fallen under critical review. Complex situations – such as the one posed in this discussion – challenge the constructs laid out in Principles of Biomedical Ethics. Additionally, ethicists hotly debate the idea of "common morality" and the application of Beauchamp and Childress' principles to non-American cultures.^[5–7]

This discussion will briefly explore the legal aspects of organ donation in the United States, including presumed and informed consent, and the bioethical principles that may direct medical decision-making in the case of an unidentified potential donor. Additionally, there will be discussion about how cultural differences (e.g. between the United States and Europe) may affect decision-making in these cases.

2.1 Organ donation and the law

The Uniform Anatomical Gift Act (UAGA) of 2006 revised previous Acts of 1968 and 1987. The Act has been enacted in all but two states at the purview of the state legislature. It states that organ donation is done after death is declared, is voluntary, and requires consent. This type of consent is not equivalent to full informed consent required for medical procedures, and in 2011, the Organ Procurement and Transplantation Network (OPTN) and United Network for Organ Sharing (UNOS) Organ Procurement Organization Committee proposed changing the word "consent" to "authorization" to be consistent with the rest of the verbiage in the Act. Overall, it is believed that the 2006 revision to the UAGA sought to increase the supply of donated organs in response to an increasing and overwhelming demand.^[8]

Donation authorization can come from any medical decision maker for the patient, next-of-kin, or, in rare cases, "any other person having the authority to dispose of the decedent's body".^[9] In this case, the hospital administration was permitted to dispose of the unclaimed body, and therefore, the hospital administration is given the legal authority to give approval to organ donation.

2.1.1 Presumed consent

In the case of unidentified individuals without known intentions for organ donation, one must pose the question: What is a person's "default" response to the question of organ donation? More accurately, this should be posed as a question that relates to the overall gestalt of the surrounding culture: *What is society's view of organ donation, and what decision can the rational, competent adult be expected to make with regards to the practice?* This question should guide decision-making after the death of an unidentified person.

The simplest method of resolving unclear intentions about

organ donation is "mandated choice," which requires patients to indicate their wishes systematically. However, trials of mandated choice have been ineffective in recruiting potential donors, as nearly 80 percent of participants in mandated choice programs choose not to become donors.^[10] Therefore, it has been largely abandoned as a method for increasing potential donors.

In the United States, organ donation is based on expressed consent, also described as "opting in".^[11] Citizens can indicate their wish to donate their organs when applying for a driver's licenses, by writing it into an advance directive, by verbal contract, or by any other means they wish. An opt-in structure is most likely based on the idea that a system built to maximize autonomy would require explicit action in order to remove one's organs after death. In other words, it is assumed that people would, at baseline, wish to keep their organs unless they indicate otherwise.

However, opt-in systems are not universal across the world. In some health systems, patients are required explicitly to opt out of organ donation if they decline organ procurement after death, as they presumably consent to organ donation if they do not indicate other intent. Although presumed consent has not been adopted in the United States, it has been widely implemented across Europe. Outcomes research from these countries suggests that opt-out systems can significantly increase donation rates.^[3]

The UAGA appears to use presumed consent in the case of unidentified persons, according to the relevant wording in the Act. In Section 9(a), the UAGA notes that if typical decision-makers are not available to consent to anatomical gifts on behalf of the patient, other decision-makers may include anyone acting as the guardian of the decedent at the time of death and any other person having the authority to dispose of the decedent's body.^[9] However, the Act does not specify who qualifies under this provision, and it leaves definition of these roles to other laws. Certainly, hospitals in possession of unidentified corpses would qualify as having the authority to dispose of them. And, since hospitals report potential donors to Organ Procurement Organizations (OPOs), this de facto sets in motion the organ donation process for unidentified bodies.

2.1.2 Informed consent

The use of presumed consent assumes that the population is properly informed of the benefits and risks of organ donation. Put another way, to presume that people are willing to donate their organs, one also presumes that they know what the process entails and would opt out if they did not find that process agreeable. After all, organ donation is a medical procedure and would fall under the purview of the regulations that govern all medical decision-making. Since informed consent is necessary before any medical treatment – particularly medical procedures – it would then be necessary for the public to be wholly informed of organ donation practices. In a written commentary on the topic, Dr. David Greer noted, "signing an agreement to have 'organ donor' printed on our driver's license at the Department of Motor Vehicles would have to be considered an extremely limited form of informed consent".^[12]

Since presumed consent relies heavily on preexisting informed consent, a lack of standardized public education may invalidate the presumption of a person's intention to donate. The practice of informed consent is built on a respect for patient autonomy, and it implies a trust in patients to make educated decisions for themselves.^[11] The removal of informed consent from the equation compromises patient autonomy and may tread on questionable ethical ground.

2.2 Bioethical principals of the case

2.2.1 Cultural differences in bioethical constructs

Bioethical exploration of a scenario can typically be viewed from four prima-facie vantage points based on the principals proposed by American bioethicists Tom Beauchamp and James Childress: autonomy, beneficence, non-maleficence, and justice.^[4] Each of these principals must be considered both independently and in combination when presented with ethical dilemmas. Beauchamp and Childress suggest that, should any of these principles contradict another, they should be balanced according to "practical wisdom" and within certain constraints.^[4,6] However, this balanced logic becomes tenuous when applied broadly and across cultures, given that moral frameworks, interpretations, and the weight given to these different principles vary across the world.^[6]

The recognition of such significant variation directly opposes Beauchamp's assertion that these four principles contribute to a "common morality," or a "set of norms shared by all persons committed to the objectives of morality," ostensibly around the world.^[13] However, bioethicists often critique this concept with a variety of questions that challenge the basis of common morality: How much agreement (i.e. 95% of people? 99%?) is necessary to qualify a belief as "common?" Is the society referenced by the common morality confined by political, geographic, or religious restraints? When the common morality is considered universal, is it also considered timeless?^[5, 14]

Jacob Rendtorff and Peter Kemp are two Danish philosophers who have taken issue with the applicability of Beauchamp and Childress' model in Europe, and their dissent is particularly notable because it comes from within another Western system. Their model also employs four ethical principles: autonomy, dignity, integrity, and vulnerability.^[7] It aims to "provide a normative framework for the protection of the human person", and Rendtorff specifically adds that these four principles "may be mobilized to protect the 'privacy' of the human person confronted with technological development".^[7] Whereas Beauchamp and Childress' model could be interpreted as more directly addressing societal needs and expectations (e.g. in the form of distributive justice), Rendtorff's description of this alternate model uses language that focuses more strongly on patient-driven conditions (e.g. dignity and vulnerability).

This may signify an important difference between American and European thinking, thus directly contradicting Beauchamp's argument for a common morality. More practically, it implies that the results of decision-making in complex situations – like a case of organ donation in an unidentified person – may differ greatly between otherwise-similar communities. With these differences in mind, the rest of this discussion will focus on the most salient ethical approaches where the case presented: the United States.

2.2.2 Case-specific bioethics

Autonomy is commonly defined as the patient's right to selfdetermination, and in the United States patient autonomy is widely considered to be the primary driver of bioethical decision-making. For this construct to be fully recognized, patients must possess some degree of the following: an understanding of treatment options and consequences, a clear preference for a treatment path, and an ability to make their wishes known. Additionally, decisions driven by autonomy require health professionals to act in the best interests of their patients, taking into account privacy, confidentiality, and informed consent.^[7] This is rooted in the French philosopher Paul Ricoeur's ethical aim to guarantee "the 'good life' with and for others, in just institutions".^[15, 16]

The idea of "ownership" of one's own body is what drives the unease behind decisions such as these. A person's body is considered to be his or her property, and this comes with certain rights. Legally, "the privacy of one's body is generally held as sacrosanct by American courts," and this is strongly rooted in the concept of autonomy.^[18] This is also the reason people may reserve the right to refuse organ donation without concern for legal action should any harm come to others from such a refusal (demonstrated in the case of *McFall v Shrimp*).^[18] Tony Honoré recognized eleven legal relations to help define ownership in modern capitalism. From these, scholars have developed a list of rights to biological materials under the assumption that one "owns" his or her body.^[19] Two are particularly applicable here: the right to security in

life and the right to security after death. The right to security in life states that a person may keep a part of his or her body and not have it removed without agreeing to it. Additionally, the right to security after death states that a person may have his or her deceased body disposed of in any way he or she wishes.

Practitioners are duty-bound to acknowledge the patient's expression of autonomy and, in most cases, to follow through on such wishes. Practitioners are not compelled to deliver care that is clearly deemed inappropriate or futile. Conflict can often arise in cases where patient autonomy conflicts with practitioner duties to non-maleficence, beneficence, and justice. Especially in the case of unilateral decision-making (as in this case), practitioners may pause to consider these other three bioethical tenets before taking irreversible clinical steps. The ICU faculty in this case appropriately paused after noting that the patient was clinically declining and called for a bioethics consult to assist in decision-making.

Both beneficence and distributive justice would suggest that a more utilitarian effort to procure organs would benefit the most people and provide a gravely ill population with the resources it needs to survive, no matter the implications for the autonomy of unidentified individuals. In 2004, the Institute of Medicine (IOM) was asked to review modern organ transplant practices, and the result was a report called *Organ Donation: Opportunities for Action.* One published response to this report noted, "the committee appears to have been dominated by ethicists, and their views of ethics, in turn, dominated the deliberations. Now certainly, I would not favor obtaining more organs in an unethical manner... But is it ethical to continue to permit patients to die waiting for organs when their lives might be saved?"^[20]

The case highlights the issues of trust and the duty to donate organs by the deceased patient. From a purely deontic perspective, society does have a duty to donate unless there is some compelling contrary reason, such as religious conviction. If one member of society has a duty to donate, one would expect that all members should be considered for donation. This is an example of a type of justice described by John Rawls as an example of the "social contract".^[21]

On the other hand, in the absence of a patient's ability to express her wishes (i.e. exercise autonomy), does the overwhelming societal need for her organs tip the scales of medical decision-making towards beneficence and distributive justice? Does a patient lose her autonomy, valued so highly in this society, only because she is unable to voice her intentions?

People are placed in a very vulnerable position when they

are classified as patients. Given this state of vulnerability, the issue of trust becomes important for the person to feel that they are well cared for, and that their needs and wishes are closely observed. In cases where organ procurement occurs without patient consent, trust of the healthcare organization within the community is greatly compromised and this has the potential to negatively impact the future willingness of the population to agree to organ donation. At minimum, one can argue that the healthcare system may be perceived as having conflicting interests, as it attempts to serve both individual patients and the public as a whole.

3. CONCLUSIONS

Technological advances have allowed for maintenance of the **CONFLICTS OF INTEREST DISCLOSURE** body on life support machines for a period even after death The authors declare no conflict of interest.

has been declared. Once a diagnosis of brain death is made, in the absence of advanced directive, all decisions about the future care of the body and organs must follow from a surrogate decision maker. In the absence of a surrogate, the final decision as to how to approach organ procurement is controversial and unsettling for many practitioners. It involves a complicated and often disputed set of ethics that may differ depending on location, personal politics, and culture. Healthcare organizations must ensure that the rights of the patient remain at the center of all decisions regarding organ donation. They must also make certain that their actions are both moral and lawful, potentially with the help of institutional ethics committees.

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