Jahi McMath: Biomedical Ethics Case Study of Law, Economics, and Technology

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Modern medicine in the late twentieth century through the twenty-first century has relied on the principles and rights outlined by biomedical ethics to govern the evaluation, prognosis, treatment, and care of patients by medical physicians. The foundation of biomedical ethics seeks to provide clear, comprehensive, coherent, and practical guidelines for medical treatment and care. However, with the advent of powerful medical and technological advancements, extending life past its natural bounds is now possible and, in the minds of many physicians, patients, and patient families, is completely permissible. This has caused much confusion, debate, and disagreement about the legality involved in such important medical decisions about life and when it has ended. In conjunction with this sudden technological empowerment and legal perplexity, there arises the question of economic responsibility and duty. These three factors – technological empowerment, economic burden, and legal perplexity – in combination with the biomedical principles of respect for autonomy, nonmaleficence, beneficence, and justice have important contributions when considering the case of Jahi McMath. Jahi McMath is a thirteen-year-old Oakland, California girl who was put on life support after she was pronounced brain-dead following a routine tonsillectomy procedure.

On December 9, 2013, Jahi McMath underwent a combined sleep apnea and tonsillectomy surgery. After the procedure, Jahi experienced serious complications including heavy bleeding and cardiac arrest that led to brain swelling. On December 12th, Jahi was pronounced legally brain dead by the physicians at Children's Hospital Oakland. Jahi's deeply religious family requested that she be kept on life support and be provided with life sustaining treatment as long as she had a pulse. However, this request was met with opposition by the hospital physicians who asserted that Jahi was legally dead and no longer required ventilation. As summarized in a legal motion filed by the attorney's representing the hospital: "There's no violation of any constitutional or statutory rights raised for the first time in this court because there is no parental, religious or privacy right to reject the scientific definition of death developed by medical professionals and enacted by the California legislature into state law with appropriate safeguards" (Alund et al., Oakland Tribune in Contra Costa Times).

The family appealed to the federal courts which, in turn, ruled in the McMath's favor by ordering a temporary restraining order against the hospital. Children's Hospital Oakland refused to perform a tracheotomy and gastrostomy, two procedures that would work to maintain the state of Jahi's body by providing more long term solutions for oxygenation and nutrition while her body remains its vegetative state. Hospital spokesperson Sam Singer made the hospital's position known: "Very sadly she's deceased and there's nothing anyone can do to change that status….We're going to fight in court to see if we can get the right thing to be done, which is to finally find peace for the body"(Alund et al., Oakland Tribune in Contra Costa Times).

In December, Jahi's mother Nailah started an online fundraising campaign seeking funding assistance for Jahi's expensive transport from Children's Hospital to a long-term facility because her medical insurance would not cover the cost (Kearney, Routers). During this time, the McMath family also petitioned the hospital for Jahi's medical records, which the hospital had not released despite the family's numerous formal requests (Bender, Oakland Tribune in Contra Costa Times). On January 3rd, three weeks after Jahi was pronounced brain dead, the courts ruled that Nailah was allowed to remove her daughter from the hospital. However, the courts denied her request that Children's Hospital be court-ordered to perform the tracheotomy and gastrostomy (Alund et al., Oakland Tribune in Contra Costa Times). On January 6th, Jahi was transported to an undisclosed medical facility in New Jersey where her deteriorated body underwent the two procedures to maintain the viability of her organs. Jahi has been kept at this facility since January 2014 amidst the numerous evaluations and statements by unbiased neurologists who claim that the girl is completely brain-dead, incapable of recovery, and physically deteriorating as time passes (Alund et al., Oakland Tribune in Contra Costa Times).

This story is only one example of many biomedical cases that have questioned the legal definition of “dead” and its clinical presentation. The formulation of this question has been made possible with the creation of medical and technological advancements. Such devices and procedures like ventilators, IV nutrition, gastrostomy, tracheotomy, intubation, and cardiopulmonary bypass have made it possible for physicians to maintain blood flow, oxygenation, and nutrition in a person’s body when his or her brain is either temporarily or permanently incapable of doing so. These procedures are commonly used to assist a patient’s recovery or to sustain further treatments that work to improve his or her health. However, these procedures have come under criticism when used in cases in which a patient is medically and scientifically known to be incapable of recovery. In this way, the tenants of biomedical ethics factors into the discussion.

The technological advancements that aid in extending life are fraught with the philosophical and ethical concerns of what *can* be done versus what *should* be done. Ventilators, tracheotomy, gastrostomy and other such procedures and devices have broadened the spectrum dramatically for what *can* be done for patients. Patients’ bodies can now be intubated, fed, and, to a certain extent, maintained even after their brains are electrically and chemically determined to be dead. Technology has made it possible for physicians to extend the body’s viability beyond brain death. However, the ultimate question of what *should* be done for any given patient remains to be seen. The question of what *should* be done has become more contested and confused since the advent of medical technological advancements. Technological advancements in healthcare – initially intended to save lives, protect bodies, and treat illness fastidiously – are now extending lives past their “proper” means of sustainable survival. Thus, technology has created a realm of healthcare in which the body is allowed to deteriorate in a manner that opposes the ethical principles of non-malfeasance, to do no harm, and beneficence, to do good for the patient.

The technological advancements that prolong life give the families of brain-dead patients inappropriately placed hope at the expense of the patient’s quality of being and end-of-life dignity. Families like the McMaths are encouraged by cardiac activity and visible signs of inhalation. They take these markers as indications of viable life and tangible predictors of a future for their brain-dead relative. Because of this, the family becomes very emotionally involved and fails to see the true effects that their decisions have on the bodies of their relatives. When the body is sustained by methods derived solely from technology, instead of the workings of one’s natural physiology, the quality the body itself is diminished. Eventual deterioration occurs as the body’s functioning shuts down due to insufficient blood circulation and inadequate nutrition despite IV feedings. This is an act of maleficence insomuch that the patient is being harmed for no justifiable end – the body is extended past its prime without any scientific evidence that natural animation will ever be restored in the future.

The family’s subjective response to the illness of their loved one alters their decision-making ability, thus leading to actions made on behalf of the patient that are not in the best interest of the patient. Aristotle denoted such a situation as “right state versus right motive” (Beauchamp and Childress 64). In this situation, the McMath family is unable to make the ethically correct choice – to remove the patient from the technologically sustaining life support – and thus the body is allowed to deteriorate. The family is not in the right state of mind: their decision-making is subjective, clouded with emotional connections to the patient. Additionally, the family is lacking the proper motives in keeping Jahi on life support. The family believes that the end result of their continuation of medical care is Jahi's return to consciousness and a state of being that is similar to that which she had before she entered the hospital. When she was first admitted, the family ardently asserted their belief that Jahi would be released for Christmas to open her presents and spend time with the family (DeBolt and Hurd, Oakland Tribune in Contra Costa Times). This family's end motive is to keep Jahi "alive" in the manner in which she was living before she entered the hospital, despite the fact that science, doctors, and technology all indicate that she will not live in that manner ever again. In reality, according to all of the physicians that have treated her, Jahi will continue to live in a vegetative state for the rest of the time that her body is sustained. Her end condition will only deteriorate, not improve. In this way, the McMath family does not have the "right" mindset to make the most important decisions concerning Jahi.

Because of this, the physicians involved in this case had to make what Pellegrino and Thomasma term "clinical prudence" decisions, decisions free from subjectivity, made with the goal of attaining an inclusive and correct diagnosis based on strict medical protocols and standards, in order to maintain ethical beneficence of treatment of a patient deemed brain dead (136). The physician is called to make a virtuous decision based on what he/she believes is the best treatment as determined by technology itself: quantitative data, patient symptoms, patient history, possible treatment, and the evidence for proper action for best result (Pellegrino and Thomasma 136-137). With this body of clinical data, the personal details of each case, and clinical prudence, the physician is able to make the proper decision for the management of healthcare. The physician is in the "right" state of mind and has the "right" motivation to achieve the best possible outcome for the patient. In this way, the physicians involved in the McMath case carefully considered the clinical data: Jahi's lack of neurological activity, unresponsiveness to stimulation, and continued physical deterioration. From this they determined that the best, most beneficent and non-malevolent manner to treat Jahi was to remove her body from all life-sustaining treatments.

Economic factors represent the second area of issues that were involved in the details of Jahi's treatment. Because Jahi was deemed medically and legally "brain-dead", the McMath's insurance provider would not agree to cover expenses that were involved in any transport from Children's Hospital or further care that would extend the functioning of her body. As a result, Nailah started an online fundraiser in order to finance Jahi's medical treatment. In this way, the insurance company maintained ethical justice in their appropriation of funds. By withholding financial support for Jahi's transport and treatment, the insurance company was able to put that money towards assisting the medical needs of another patient for whom treatment would be of beneficent action. Because any medical treatments for Jahi would only result in the extenuation of her legally deceased body and thus be a practice of maleficence, funding such efforts would be ethically unjust in the viewpoint of the insurance company.

The economics involved with Jahi's case were appropriated according to a justice scheme determined by the need of the patient. The insurance company, following the medical evaluation made by the hospital, determined Jahi to be legally brain-dead and therefore, not able to return to a consciously living state. Therefore, after her procedure, Jahi was no longer in need of medical treatment because her medical condition was untreatable. Additionally, any further medical treatment – continuation of care, ventilation, tube feedings, IV hydration etc. – would only work to extend the time her body was allowed to deteriorate. Because of this, the insurance company determined that any economic funding of further medical intervention into Jahi's case would violate the principles of biomedical ethics in two ways. The first violation of ethics would be due to a breaching in the code of nonmaleficence: continuation of medical treatment would only permit the body more time to deteriorate slowly in an undignified manner. The second violation of ethics would be due to disregard of the code of justice: dispensing economic assistance to a patient who does not need medical care, and therefore does not need financial assistance. Therefore, the insurance company adhered to the principles of justice to each, according to need, when distributing economic assistance to patients including Jahi.

Law and legality represent the third realm of issues involved in the McMath case. Questions regarding the autonomy of the patient, the family's right to medical records, and the hospital's right to deny Jahi life-extending medical treatments all played a very large role in the development of this situation. The McMath family engaged in a public battle with the hospital regarding Jahi's medical records, specifically the issue of malpractice and its possible dissimulation by the physicians (Bender, Oakland Tribune in Contra Costa Times). The hospital asserted that they needed to receive a signed, formal request form from Jahi's parents in order to release her medical records. This delay was apparently caused by their policy that permits them to withhold records for all patients at the time of their active care at the hospital. According to this policy, once the patient is released from the hospital, the records become available to the patient and his/her representatives.

This policy on behalf of the hospital is an act of violation of Jahi and her family's rights because Jahi is a minor and as such her family is in charge of her medical care (Beauchamp and

Childress, 72). As Jahi's representative and medical liaison (considered further in the following discussion), Nailah had the right to her daughter's medical records in order to understand her daughter's condition and all of the risks/benefits of certain procedures (Beauchamp and Childress, 70). By withholding this information, after Jahi suffered brain-damage, the hospital still violated the rights of the patient. While Jahi was under the care of Children's Hospital, Nailah had the right to understanding all of the Jahi's past medical treatments. In this instance of the case, Children's Hospital failed to uphold Jahi's rights when she was unable to defend herself and while she was in a state that required immediate dissemination of health information to her healthcare proxy, Nailah.

In this case, the Jahi's mother represented her daughter because Jahi is a minor and, after the complications with her surgery, also unconscious. Because of these two factors, Jahi is a patient deemed unable to make autonomous, independent decisions for her own medical treatment. According to the hospital staff, the Jahi's representative signed an informed consent form (DeBolt and Hurd, Oakland Tribune in Contra Costa Times). In this way, the patient representative, and, by proxy, the patient consented to the surgery and to any complications derived from the procedure. In the immediate aftermath of the procedure, the hospital continued to support Jahi's right to life by intubating her and maintaining her vital functions. Jahi's representative consented to this positive right to healthcare (Beauchamp and Childress, 72). Therefore, the hospital was successful in maintaining and protecting the autonomy of the patient to the best extent possible prior to and following the surgical procedure.

However, once Jahi was pronounced brain-dead, her mother took issue with the hospital when the facility claimed their negative right to refuse the girl further treatment. A negative right "…entails another's obligation to refrain from doing something" (Beauchamp and Childress, 73).

In this situation, the hospital and Jahi's healthcare providers chose to pursue a rights-based ethics approach to treatment. According to rights-based ethics, obligations to act or to provide care are derived from rights, not the reverse (Beauchamp and Childress, 7). Therefore, the hospital had the right to refuse care to Jahi based on their determination of her medical condition, future prospect for recovery, and oath to follow the practice of beneficence. Jahi's right to just treatment and nonmaleficence permitted the hospital to follow their right to deny services that would extend the bodily functions of a brain-dead patient. As a result, the hospital did not have the obligation to perform medical treatments on Jahi's body and exercised their negative right of treatment.

Clearly, the societal constructions of technology, economics, and law intersect in multiple areas in the deliverance of medical care that maintains autonomy, beneficence, nonmaleficence, and justice for the patient. The technology that saves lives and gives new opportunities of life to those on the brink of death comes at the high ethical cost of giving desperate and ill-informed families the choice to prolong life that ethically should not be. The economics of healthcare delivery provide a pathway for insurers to selectively provide financial aid to those who are justly due assistance according to their need. In this way, insurers are able to assist the delivery of beneficent healthcare to those who display the most need in society. Finally, the legislation surrounding bioethical healthcare delivery ensures both the rights of the healthcare provider and the patient themselves. The patient has the right to their medical records, information, prognosis, and autonomy. The healthcare institution has the right to proceed in an ethical manner that will increase a beneficent outcome while following a protocol of overall nonmaleficence. Accordingly, the healthcare provider has the legal ability to follow a system of negative and positive rights when distributing healthcare to their patients. Jahi McMath suffered a terrible injustice of statistics. According to Office of Statewide Health Planning and Development, only 1.7% of patients undergoing tonsillectomies in California experienced hemorrhaging between 2008 and 2012. This number is even higher than the 1.4% reported at Children's Hospital Oakland, the hospital where Jahi had her procedure performed, during that same time period (Gafni, Contra Costa Times). However, this injustice does not extend to include the actions on the part of the hospital. Children's Hospital maintained its practice of beneficence and nonmaleficence in choosing to legally follow their negative right to deny Jahi medical treatment that would only allow deterioration, not healing, of her body. The hospital followed bioethical protocol while maintaining the autonomy of the patient and her family representatives. Although the hospital did not perform the actions for which the family urgently demanded, the hospital did follow the ethically sound course in conjunction with technological, economic, and legal factors.

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