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CASE STUDY: THEORETICAL ETHICS

Does Technology Warrant Absolute Power of Religious Autonomy?

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Abstract: *Investigating an actual case that occurred in a New York state hospital where an Orthodox Jewish patient's legal proxy demands that the clinicians and hospital administrators should provide aggressive treatment with all available technological resources for the seemingly brain-dead patient with a medically futile condition. The authors argue that a health care policy or regulation should be developed to limit patient's access to technology in critical care. Otherwise, we will be allowing society to issue a carte blanche to religious autonomy by technology abuse. It is argued that religious autonomy should be restricted when its demand exhibits apparent logical absurdity and/or goes against the common survival of the entire population.*

Keywords: *Technology, medical futility, end of life, critical care, religious autonomy, the First Amendment, Orthodox Judaism, Jehovah's Witnesses.*

INTRODUCTION

In today's health care industry, advanced medical technology poses ethical dilemmas which constantly challenge clinicians and health administrators. What follows is an actual case that occurred in a New York state hospital. The case was discussed in the hospital's ethics committee meeting although a formal ethics recommendation was never received. We will investigate the case by reference to various moral concerns, and argue in conclusion, that ethical and legal discussions should be furthered to develop and implement a health care policy or regulation to limit patient's access to technology in critical care, so that the technology is not used as a carte blanche issued to religious autonomy.

CASE

A 70-year-old male was brought into the ER with EMS after being found unresponsive in an Endocrinologist's office. The patient had an extensive past medical history, including diabetes, hypertension, coronary artery disease, and peripheral vascular disease. CPR was initiated by the office staff and upon arrival of EMS, the patient was noted to be in a pulseless electrical activity (PEA) rhythm. The patient was intubated and advanced cardiac life support (ACLS) protocol initiated. Upon arrival to the ER, the patient had regained a rhythm but did not regain consciousness. Multiple episodes of ventricular tachycardia (VT) and ventricular fibrillation (VF) occurred, requiring defibrillation and initiation of multiple IV medications. Hypothermic protocol with Artic Sun was started even though the patient's pupils remained dilated and fixed. A CAT scan of the head revealed loss of grey white differentiation suggestive of edema and anoxic brain injury. The neurological exam was also consistent with significant anoxic brain injury.

The patient had no advanced directives, legal spouse, or children. Thus, the patient's next of kin, his biological sibling, became his Health Care Proxy (HCP). Despite the patient's extremely poor medical prognosis, that is, an end-stage condition, the HCP wished to continue all aggressive measures for the patient. The patient presented with fixed dilated pupils which represented a poor prognostic sign post cardiac arrest. The Palliative Care team explored this at length with the HCP and advised a terminal compassionate wean, but the HCP refused. The HCP and the patient were Orthodox Jewish, and the HCP reported that their religious belief did not allow to stop the treatment. It was understood later by the staff that the HCP also believed that the patient's current suffering would be atonement for the sins he committed during his lifetime. Attempts were made by the staff for the HCP to meet with the hospital rabbi to discuss the matter. The rabbi made suggestions, but the HCP refused.

A neurology team suggested performing an official brain death exam to determine whether the patient is brain dead. According to New York State, a patient can be legally pronounced brain dead by the official apnea test along with clinical examinations, and the law does not state that the healthcare providers should obtain informed consent from the HCP to perform the official apnea test on the patient but that the providers are to make "reasonable efforts" to notify the HCP that the evaluation for brain death is underway.¹ Thus, the neurology team informed the HCP of their plan on the test but the HCP adamantly refused, repeating the religious reason – Orthodox Judaism acknowledges only cardiac death. Thus, the team respected the HCP's wishes and ceased to perform the exam.

More invasive care continued without measurable medical benefit for the patient. Soon, hemodialysis was considered to stabilize the patient's condition. The medical team consulted with the hospital rabbi, and the rabbi agreed not to start dialysis. However, the patient's HCP remained adamant to "do everything." Dialysis was initiated and the patient also received a tracheostomy and peg tube placement. The patient continued to require multiple IV medications for blood pressure support and life-threatening arrhythmias. In addition, runs of VT/VF during dialysis required defibrillation. The advanced treatments and aggressive care continued with multiple sequelae, void of clinical evidence of neurological improvement. The ventilator assisted his respirations but, within two weeks, ventilator assisted pneumonia (VAP) erupted requiring antibiotics. The IV medications that maintained his blood pressure resulted in lower extremity ischemia and necrosis of tissue. The initiation of dialysis resulted in ventricular arrhythmias requiring recurrent defibrillation. As we continued this futile medical treatment without any signs of neurological improvement, the patient had a cardiac arrest during dialysis but could not be resuscitated. The patient's body finally expired after two months since the time of admission.

RELIGIOUS AUTONOMY UNDER THE FIRST AMENDMENT PROTECTIONS

As patients are more informed and the power of self-determination is increasingly valued in our culture, patient autonomy, today, is most associated with patients' right to withdraw or continue treatment, and healthcare providers are deemed legally and ethically bound to respect the patient's autonomous wishes. This case looms large when it comes to the issue of religious autonomy. In the U.S., patients' wishes grounded on religious beliefs are protected under the First Amendment rights, even though the faith-based wishes may conflict with the clinicians' medical advice and sincere ethical concerns. The Free Exercise Clause of the First Amendment referred to as a guarantor of religious freedom in healthcare is controversial, as the federal Supreme Court is reluctant to address its rightful interpretation while federal circuit courts and state supreme courts have been left to wander off into their own legal pastures. What is practiced now is that under the legal rule of thumb (that is, the religious freedom to believe is absolute but the right to act on that belief is not) the courts decide what to do, case by case.² Meanwhile, the fear of lawsuits among healthcare professionals seem to give a free pass to the patients who demand religious autonomy under the First Amendment rights – we qualify, however, that the medical professionals' efforts of complying laws and subsequently of avoiding lawsuits is not merely a fear of financial loss, ethically unjustifiable, but should be taken as an ethical concern in and of itself in the sense that the laws serve as an ethical threshold.³

In our case, coming from the Orthodox Jewish belief, the patient's HCP demands that the clinicians continue to provide the patient with an aggressive, yet futile medical treatment against the healthcare providers' medical advice and earnest ethical regard.

¹ New York State Department of Health, "Guidelines for Determining Brain Death," Nov. 2011, accessed May 17, 2017, https://www.health.ny.gov/professionals/hospital_administrator/letters/2011/brain_death_guidelines.pdf

² Reynolds v United States 98 US 145, 166 (1878); Employment Division Department of Human Resources v Smith, 494 US 872 (1990).

³ It has become a cliché to say that law has replaced ethics particularly in a hospital setting. On the other hand, we understand that healthcare laws change and evolve due to ethical concerns, which makes ethics an irreplaceable, fundamental blue print for the laws. The relationship between ethics and law, in fact, is a perennial topic in jurisprudence, philosophy of law. One way of understanding the relationship between the two is to see law serving as a tool to secure ethics bottom-line. For more discussions that ethical documents are replaced by legal counterparts, see Stefan Eriksson, Anna T. Höglund, and Gert Helgesson, "Do Ethical Guidelines Give Guidance?: A Critical Examination for Eight Ethics Regulations," *Cambridge Quarterly of Healthcare Ethics* (2008) 17: 27.

The well-known religious tenet of the Orthodox Jewish denomination (i.e., human life begins upon the first breath, so does death arrive upon the last breath) makes the patient's religion so unique that we should treat the Orthodox branch distinct from other Jewish denominations such as the Reformed or Conservative Judaism, at least with regard to the issue. In Orthodox Judaism (henceforth OJ for "Orthodox Judaism" or "Orthodox Jewish"), since life begins upon the first breath, a human embryo or fetus is not considered a human person. Thus, abortion, in general, is considered a personal choice. And a human person is considered dead when his or her breath departs, so cardiac death is only regarded as theologically licit. Concerning physical sufferings, there can be more than one interpretation, but it is a legitimate OJ view that human beings are to atone for their sins through physical sufferings in their way to death.⁴ Many OJ theologians endorse retributive theology to explain the relationship between sins and suffering – that is, sins are the causes of all sufferings and the repentance of those who commit sins necessarily involves divine punishment. This is consistent with the theological ethical direction in which any OJ believers might go, to say that physical sufferings we embrace in our last stage of life are a purgation of our sins.

We are not arguing here that the HCP's position shown here is representative of the majority OJ believers' opinion, or of the OJ authority's view if we can locate one. Rather, we are stating that the HCP's view can be a legitimate OJ position. It is interesting to note that in our case the hospital rabbi asked to assist the HCP is a medical staff in the hospital and identified himself as OJ. He confirmed that the patient and the HCP were both OJ and recommended that the HCP should follow the medical team's advice, though the HCP denied his advice. It is possible that the staff rabbi opined contrary to a standard OJ opinion or that the HCP voiced against what may be the majority OJ view. But again, our point is that the HCP's position can be justifiable as a legitimate OJ view because it is consistent with the traditional OJ teachings shown above. Besides, it is not uncommon to us that the view of many OJ patients in end stage is highly similar to that of the HCP.

THREE CONCERNS

Three immediate concerns arise. First, it is rationally difficult to comprehend the possibility that the patient, in our case, is suffering as atonement made for his sins, even though we may concede to their view that the patient is alive. The patient is unconscious (persistent vegetated state or minimally conscious state, if not coma or brain dead) and thus not deemed exposed to physical sensations. In other words, the patient not only lost his cognitive power but also is immune to the acute pain and tremendous discomfort that otherwise his healthy mind and body would have experienced. Second, related to the first, this case makes the medical professionals' beneficent and nonmaleficent duties toward the patient lose any ethical significance. What does it mean to say that clinicians are striving to help their patient or to not cause the patient harm when the patient lost his entire cognitive, cognitive, and emotive powers while his physical condition is rapidly and irreversibly deteriorating? Any meaningful sense of helping or not harming the patient cannot apply here. Third, from the standpoint of distributive justice, keeping alive the medical futile patient is an unfair allocation of health care resources, that is, the manpower and money spent on complex life sustaining machines and surgeries. As all hospitals primarily serve a local community within their own geographic boundaries, the resources spent here would have been utilized to help the other members of the community.

A CONCERN ABOUT TECHNOLOGY AND THE SOCIETY'S DECISION TO CONTROL

However, the three concerns above are ultimately tied to the fundamental regard which demands our prudence in drawing limits on patient's accessibility to medical technology. How far is too far when it comes to prolonging life for this patient by use of technology? We should accept the fact that the patient would have faced natural cardiac death long ago had this extreme, bizarre technological intervention not been initiated. Conversely, had the HCP's access to the technology been limited in the first place, the treatment would not have been initiated and thereby no question could arise about the First Amendment right related to the patient's religious autonomy.

⁴ The relationship between physical suffering and sins was explored rather extensively among the modern Jewish scholars after the Holocaust. Among them, many scholars held the position, based on their traditional, retributive theology, that the Holocaust is the result of human free will in the sense that the sins the Jews had committed out of their own free will were the causes of the great sufferings and therefore that God cannot be blamed for the Holocaust. Sin is the cause of all sufferings, and the sins must be punished. This is in alignment with the medical ethical position that the sufferings patients undergo in their last stage of life have redemptive quality. Bluntly put, the patients are paying for their own sins so that they would be forgiven by God. For suffering and sins, See Sara E. Karesh and Mitchell M. Hurvitz, "Reward and Punishment," *Encyclopedia of Judaism* (New York: Facts on File, 2006), 426; also, Arthur Allen Cohen and Paul Mendes-Flohr, *20th Century Jewish Religious Thought: Original Essays on Critical Concepts* (Philadelphia, PA: The Jewish Publication Society, 2009)

It is not that medical technology in and of itself is extreme and bizarre. Technology is good and can save many people's lives. But when used to treat the incompetent, end-stage patient whose condition is clearly medically futile,⁵ technology loses its intended purpose. We need the policy to control technology; otherwise, we are to give religious autonomy the warrant of absolute power. In our case, the ethical-legal threat related to the First Amendment, in other words, is a self-made problem, due to the absence of pertinent legal regulations.

A Legal Reasoning and Coercion: The Cases of Jehovah's Witnesses' Children

One may be pessimistic about engaging in legal discussions concerning religious autonomy, believing that the outcome of such activity is always hurtful to some individuals or communities. However, we believe that a constructive proposal is indeed possible. Take, for instance, cases of the Jehovah's Witnesses' children. The Jehovah's Witnesses (henceforth, JW for "Jehovah's Witness" or "Jehovah's Witnesses") believe that blood transfusion will lead to eternal damnation even though it may save one's physical life temporarily on earth. And they raise their children in accordance with this belief. However, in our society, the JW's parental refusal of blood products on their children in the hospital is highly unlikely because the state does not allow the parents to do so. In the U.S., the courts (though not at the federal level but at the state level) see the child's physical welfare as paramount. When the JW's children are young children, the legal doctrine derived out of the familiar, *Prince v. Massachusetts* (1944) is used as a legal standard – i.e., the parents may martyr themselves but they may not martyr their child before the child reaches the age of majority. Based on the doctrine, the state intervenes to protect the child's physical wellbeing.⁶

To discuss cases for teens, some U.S. states like Pennsylvania and Illinois hold the mature minor doctrine, which allows some minors to consent to medical treatment without parental consent. However, for adolescent JW, most of the U.S. courts qualify this right. They tend to adopt the United Kingdom's approach to the case. That is, because many children raised in isolated religious communities like the JW may never have experienced the outside world, "the judiciary would be wrong not to give them that opportunity. Religion is a powerful persuading voice, but it is also an individual belief. A limited life experience cannot truly give one the opportunity to rationalise a belief that may eventually lead to death."⁷ In sum, the courts in the U.S. see that teenagers' physical welfare should come first when conflict occurs over the views of the JW parents. The children may side with their parents' views when forced to be treated, but the state cannot see the adolescent JW as mature enough, due to their observed isolated upbringing.

Philosophical Justification and Theological Leeway for the Legal Reasoning

One may wonder if there are any philosophical ethical justifications for the legal coercion against the JWs and how the case is related to our case. The case of the JW children here is different from our case, but the identical philosophical ethical feature is found in both cases. That is, accommodating cultural and religious minorities' beliefs is important; however, when their beliefs are put into practice in a way contrary to a common survival of the entire population (*the ethical standard of common survival*) or in a way of exhibiting apparent logical absurdity (*the rational-ethical standard of logical adequacy*), the state's legal coercion is justifiable. Such cases are the JW children's case and ours. State and healthcare providers are justified to provide blood transfusion for the critically injured or ill JW minors, for it is rational to believe that the JW minors' faith is not of a mature, confessing kind, which is considered genuine faith. To be precise, JW minors are not JW believers yet. Thus, it is rationally absurd to impose the JW rule on non-JW believers (*the rational-ethical standard of logical adequacy*).

In our case, state and clinicians are justified to deny the OJ HCP's request, which is coercion by omission. Providing all available technological interventions to keep the OJ believer's heart beating, as shown in the three concerns above, is not only irrational (*the rational-ethical standard of logical adequacy*) but also seen as contrary to the direction in which a common survival of the population is promoted (*the ethical standard of common survival*). Alternatively put, the logical adequacy is violated when one believes that the unconscious patient with no physical sensation is atoning for his sins (*the first concern above*) or that the doctors should medically help or do no harm the patient whose cognitive, conative, and emotive capabilities are absent (*the second concern above*). And we are acting against the ethical rule of common survival when wasting medical resources to merely maintain the patient's heartbeat (*the third concern on distributive justice*).

⁵ We are using the term "medical futility" in a general sense.

⁶ *Prince v Massachusetts* (1944) 321 US 158.

⁷ S. Woolley, "Children of Jehovah's Witnesses and Adolescent Jehovah's Witnesses: What are Their Rights?" *Archives in Disease in Childhood* (2005) 90, accessed June 1, 2017, doi: 10.1136/adc.2004.067843.

Finally, the court's position above gives both the JW parents and their children a theological leeway. It is highly unlikely that the minors (young children and adolescents) forced-treated with blood products would be shunned or excommunicated from their religious community, for the patients and their parents are not held accountable ethically because the treatment *is forced*. Likewise, the HCP cannot be blamed by the OJ community because the HCP was not able to request medical treatment with all the technology on behalf of the patient when the state prohibits the access. In other words, in both cases, the blame is not on the religious members but the state.

Technology is exploding and we now have amazing machines, but this comes with a responsibility to use them wisely and for the best interest of the entire population that the healthcare industry serves. It is time for us to engage in discourses to set clear intended uses of specific medical machines and to limit their uses.

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