

The Existence of Unethical Hospital Practices When Treating Religious End of Life Patients

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Abstract:

The purpose of this study is to identify unethical hospital practices involved when treating end of life religious patients. Each day thousands of patients are admitted to hospitals due to terminal illnesses, or become end of life patients due to some irreversible complication resulting from a hospital surgery or procedure. These same patients may never leave the hospital. This is when they become classified as end of life patients. This often results in their being faced with the decision of how they want to spend their last days. The existence of patient autonomy coupled with how religious patients may define “end of life” may result in unethical treatment, whether intentional or unintentional, on the part of the hospital when these factors aren’t seriously considered, and hospitals respond with treatment based on hospital protocols. Many of these patients and family members, who are religious, are given the option to speak with hospital clergy or their own private clergy for the purpose of making this transition easier, despite the patient having already expressed their wishes in Advanced Healthcare Directives. As a result, these end of life preferences/decisions often collide or interface with hospital ethics; often causing doctors to overstep boundaries resulting in the violation of the ethical principle of autonomy. This study looks at cases involving religious patients, religious tenets as related to hospital care and other sources to identify the existence of such and to provide a solution to said unethical practices. This paper does not seek to point fingers or suggest that the existence of unethical actions of hospitals when dealing with religious end of life patients are deliberate or unintentional. It merely points to the fact that these unethical actions exist and seeks to provide suggestions for reducing or remedying them.

Introduction:

As recently as 60 years ago, the treatment of end of life patients was primarily directed by the two principles of beneficence and non-maleficence; treatments performed while acknowledging the patient's desires as well as their autonomy was virtually non-existent (Burkle & Benson, 2012). Beneficence is a concept in research ethics which states that researchers should have the welfare of the research participant as a goal of any clinical trial or other research study. The principle of non-maleficence states that we should act in ways that do not inflict evil or cause harm to others. In particular, we should not cause avoidable or intentional harm. This includes avoiding even the risk of harm. Fast forward 60 years later and just as hospitals have evolved with the waves of technological innovation, so have the ethical principles that are now considered when treating seriously ill patients. While the principles of beneficence and non-maleficence are still very much considered when treating terminally ill/end of life patients, today, the principle of autonomy, an ethical principle that is defined as "self-rule"--and as the patient's right when it comes to whether or not it is time for them to die--has become the predominate ethical principle involved in navigating the end of life patient's fate. Unfortunately, health care professionals in the US struggle with the importance of balancing patient autonomy with beneficence and non-maleficence. Their attempt to still practice under the guise of treatments based on the latter ethical principles that were most prevalent 5 to 6 decades ago are creating conflicts that can be deemed as unethical and may even lead to lawsuits due to a failure to obtain informed consent. This becomes even more difficult when dealing with religious patients, because for these patients, God calls the shots, which often results in these patients defining end-of-life far differently than that of the treating hospital. (Park, J. L. (n.d.).

Elements that Shape Hospitals Views Surrounding End of Life Care and Death

Elements that shape the way hospitals view end-of-life care are often similar to the factors involved with Medicare due to the fact that a vast majority of the 2.5 million people who die during the year in the US are ages 65 and older, which makes Medicare the largest healthcare insurer during the last year of life (*Medicare Fact Sheet*, 2005). The *Medicare Fact Sheet* (2005) provides that end-of-life care is defined by Medicare as all healthcare provided to someone in the days or years before death, whether the cause of death is sudden or a result of a terminal illness that runs a much longer course. These services include the actual in-patient care in hospitals other settings, home health care, diagnostic tests, physician services, and prescription drug coverage per Medicare part D. These services covered by Medicare may apply to curative or palliative treatments (*Medicare Fact Sheet*, 2005).

The Park (n.d.) website provided that Medicare paid \$50 billion for doctor and hospital bills during the last two months of patients' lives alone. Today, eight years later, people are living longer so that number has likely increased. This undoubtedly also shapes how hospitals view end-of-life care because the longer a patient decides to remain on life support, as is in line with their autonomy or per their advanced health care directive, then the more money is being paid out to support them during what hospitals have deemed end of life (Park, J. L. (n.d.). However, after someone is pronounced legally dead, there is no longer an obligation to continue life support or an insurance plan to pay for care notwithstanding the wishes of the family. This

allows resources to be freed up to move on to the next patient. Hospitals often define death as the cessation of brain function.

Elements that Shape Religious Patient's Views Surrounding End of Life Care and Death

Different religions contain elements that shape the religious patient's views surrounding end of life and medical treatment, and even what is considered legally dead, and thus call for differing treatments, protocols and respect for the religious person's autonomy. Many religious people believe that God chooses when a human life will end (Park, J. L., n.d.). Thus their faith affects their decisions concerning terminal care. However, under the umbrella of "religious" beliefs regarding end of life, there lies an even more specific view on end of life that is specific to each form of religion.

Linzer (2013) provides that under Jewish law or Halakha, when it comes to critically ill patients, everything must be done to preserve life and the hastening of death is forbidden. Thus, an act involving the withdrawing of life-sustaining, continuous treatments is completely prohibited. For Christians, regarding prolonging life during episodes involving fatal illnesses, the belief in miracles or the belief that God decides when people die, often defines how the Christian defines end of life. Just as Christ hung on the cross and was crucified, he prayed to Father God for guidance and said that his executioners did not take his life, but he gave it; thereafter he bowed his head and relinquished the ghost ("Bible Gateway", n.d.). Along these same lines for Christians or followers of Christ, some believe they should do nothing but pray, instead of relying on medical professionals to decide when life sustaining treatment should be removed; failing to wait on God to speak is prohibited (Pattinson, N. A., & Lee, C., 2011). The McCormick (n.d.) proffers that the biblical basis for end of life decisions on which Christians base their beliefs include the belief that as long as a person is conscious, he or she may continue to influence others through their life and prayer. Thus the Christian should not seek to abbreviate their life, but look to the Lord for strength to complete the course of life in accordance with his will (McCormick, n.d.).

Romain and Sprung (2014), provide that the Catholic Church permits the discontinuance of therapy and alleviation of pain and suffering in the dying process no matter if life is shortened as an unintentional side-effect. This principle permits exacting a legitimate act even if the act leads to a normally avoided effect, such as alleviating pain even if it unintentionally hastens death. (Romain and Sprung, 2014).

While the Muslim religion, like that of Christianity, requires that everything be done to preserve the patient's life, it is permissible to withhold therapy allowed in the terminally ill patient when there is certainty that there is absolutely no hope (Romain and Sprung, 2014).

Judaism, Islam, and Catholicism all uphold beneficence and non-maleficence. In terms of autonomy, Catholicism focuses on the patient's decision for treatment while Islam and Judaism incorporate the judgment of religious advisors in the determination of what is best for the patient's health and welfare in accordance with religious laws.

Physicians need to be aware of their patients' understanding and practice of religion and the

possibility that some procedures or treatments they suggest could seriously disregard the patient's beliefs and lead to predicaments of the patient's conscience. It is imperative to discuss the religious beliefs of patients early on in their care and especially prior to the placement of life-sustaining treatments. ("Iranian Society Of Cardiac Anesthesiology", n.d.).

In what has been termed as Christian martyrdom, Shinall (2014) intimates that the discourse of martyrdom leads Christians to choose more aggressive medical care at the end of life. His case studies recognize numerous elements in Christian living, such as the belief in miracles, or the concept that God decides when people die, which steers Christians in the direction of more aggressive treatment and divorces them from the concept that they are truly at the end of their life. At this juncture, they are holding out for more time for God to deliver. Thus, if their beliefs are overpowered by hospital protocol, often their autonomy is compromised, which leads to evidence of unethical behavior on the part of the hospital whether intentional or unintentional.

Palliative Care and Autonomy

Palliative care services were implemented in hospitals to help ensure the autonomy of chronically ill patients (Paulus, 2008). In accordance with autonomy, palliative care goals are specifically patient-centered. They include actions which seek to (1) create the best quality of life possible for patients, (2) to relieve pain and suffering through expert pain and symptom control, and (3) to guide and assist patients or surrogate decision-makers in establishing appropriate goals of care (Paulus, 2008).

Autonomy is defined as the ethical right to make one's own decisions and see them through. This is one of the most important principles used to guide a terminally ill patient because it places value on the patient's worth and allows them to decide what is best for them medically (Paulus, 2008). Respecting patient autonomy means respecting patients decisions without placing roadblocks in their way. Essentially, if it means moving away from hospital protocol in order to preserve the patient's autonomy then this is what should be done. This becomes critical when treating an incurable progressive illness and treatment decisions are less clear and depend greatly on personal values and preferences (Paulus, 2008).

When hospitals solely use standards to shape how they will treat end of life religious patients, they ultimately introduce unethical practices that discard patient autonomy when they fail to consider the patients religious beliefs. In the case of *McMath v. Children's Hospital Oakland*, after undergoing surgery for sleep apnea in December of 2013, 13 year old Jahai McMath was pronounced dead following a cardiac arrest that occurred after the surgery (Platt, 2016). After someone is pronounced legally dead, there is no longer an obligation to continue life support or an insurance plan to pay for care notwithstanding the wishes of the family (Platt, 2016). In this situation, there was a conflict between what the mother of the minor patient believed to constitute death, and what the doctors believed. Platt (2016) found that Jahi's mom argued that her daughter was in fact still alive due to her religious belief that death occurs only as the loss of cardio-respiratory functions, notwithstanding brain activity or absence thereof. This case

represented a conflict of how the hospital viewed end of life and/or death vs. how the minor patient's family viewed end of life and/or death. Once the patient was pronounced dead by the hospital, failing to recognize the family's religious views surrounding death, it can be argued that the patient's autonomy was violated. After obtaining a court order, Jahi was transferred to New Jersey because under that state's religious law she is still alive. (Platt, 2016).

Patient autonomy for the critically ill patient is not a one size fits all principle. While it may have started out like a one size fits all principle-- due to the overwhelming types of cases exercising autonomy involving cases where patients, even some being religious, wanted to be disconnected from life sustaining treatments--today the exercise of autonomy can look vastly different. This can be quite confusing for the hospital that has instilled a palliative care program to respect a patient's autonomy and has not made the provision for the religious patient who has no desire to utilize palliative care in association with his or her autonomy. In cases such as these, where autonomy for one end of life patient may mean exercising their wishes to not administer life sustaining measures, for the other patient, namely the religious patient, autonomy in a similar circumstance may look remarkably different.

Unfortunately, patient autonomy is often not considered or respected in end of life health care in either circumstance, however, the most notable cases where this reigned true has been with patients who wanted to end life sustaining treatment (Paulus, 2008). Thus the focus of corrective action and respect for autonomy has largely hovered in the area of cases where patients no longer want to preserve their lives. Studies have shown that not only have life-sustaining measures been used in cases where they were ineffective and undesirable by patients and families, but often a patient's desire to waive resuscitation is ignored (Paulus, 2008). According to Paulus (2008) palliative care services have aided in the refining and enforcement of hospital policies and procedures that honor some patient's autonomy. These policies may include: initiating advance directives, developing guidelines for Do-Not-Resuscitate (DNR) orders and withdrawing or withholding treatment, supporting comfort care procedures, and caring for patients in comas and persistent vegetative states (Paulus, 2008). How about when the patient's autonomy calls for providing whatever life preserving procedures necessary to keep the patient alive and breathing and this exceeds the hospitals scope of practice where the treatments is deemed to be too expensive or of non-effect? Or where the patient's view of how much pain and suffering he or she should endure conflicts with that of hospital protocol? How does the hospital's protocol's equally protect this patient population's autonomy?

In the Shinall (2014) study of Christian's and aggressive end-of-life care, patients and or their families were shown to often provide religious reasons for advocating for life sustaining methodologies or technologies that may be viewed by doctors as being able to provide little to no hope of restoring health. Studies have shown that religious patients facing life-threatening illnesses often choose more aggressive, life-prolonging care than nonreligious patients. Thus, patient autonomy in these cases should be approached differently or hospitals may be faced with claim of unethical practices. Where a hospital may see certain symptoms and manifestations in a patient as signals for them to follow protocols associated with those used on end of life patients when death is near, the religious patient, namely the Christian patient may see these same symptoms as a sign from God that it is time to ramp up their faith. These colliding views about the patient's state often leads to a conflict with the way end of life is defined by the hospital and

ultimately how the patient wants to be aggressively treated versus how they ultimately are treated by the hospital.

Recent cases, such as the *McMath v. Children's Hospital*, have forced hospitals to have to deal with a different manifestation of autonomy and the end of life religious patient. This has forced hospitals to informally deal with the second principle of palliative care, that of relief of suffering, as related to autonomy in a far different and more complex way than ever before. For some religious end of life patients, relief of suffering is not of concern to them and for them, especially the Christian patient, suffering for Christ's sake as he suffered on the cross becomes more important and as stated above a type of martyr story framed in an ethos of Christ's death. (Shinall, 2014).

Courts have determined that in assessing whether or not to continue life support for an incompetent patient, the best interest standard applies when the patient has never been competent or has not expressed her wishes concerning medical treatment. The "best interests standard" includes, but is not limited to, examining the patient's present level of physical, sensory, emotional, and cognitive functioning, the degree of physical pain resulting from the medical condition, treatment, and termination of the treatment, the degree of humiliation, dependence, and loss of dignity probably resulting from the condition and treatment, the life expectancy and prognosis for recovery with and without treatment, the various treatment options, and the risks, side effects, and benefits of each of those options (Jones, C. J, 2016).

In some cases, religious patients may be incapacitated by the time they have reached what hospitals deem to be end of life. However, where there is an advanced health care directive that expresses the wishes and or religion or where there is even family or clergy from their religious faith, then the best interests test would be inapplicable and that religious patient's autonomy can seek to be respected.

In a 2014 case in Nebraska, an Elderly mother's desires and her daughter's as mother's attorneys in fact under health care power of attorney, were required to act in her best interests rather than defer to her wishes. Although the mother's primary wish to remain in her home was known, it was unclear that she was competent when she expressed other desires, and it was unknown what she desired when it became impossible for her to remain in her home (Jones, C. J, 2016).

For religious patients who have made their wishes known either in their advanced healthcare directives or to their caretakers or family members, and where their desires are otherwise known, case precedent suggests that the hospital act in a way aligned with their wishes in accordance with the patient's autonomy and not according to their best interests. For the religious patient, this may vary based on the religion with which they identify, and the jurisdiction in which they reside and when hospitals fail to act in the patients best interest—as described above—and not in accordance with the religious patient's wishes, they fail to respect their autonomy, which is unethical.

Advanced Health Care Directives, Living Wills or Health Proxies

Documents that have been given legal recognition to represent a patient's end of life decisions or

wishes include a living will, health care proxy, durable power of attorney, or the all encompassing advanced health care directive. End of life decision making is substantively governed by the laws of a state in that particular jurisdiction. All states now have some legislation addressing end of life decisions, which includes advanced healthcare directives.

Living wills provided the first attempt by people to control their end of life decisions in writing while they were still competent, however, most predate most states legislation surrounding these issues and thus are given no real legal recognition by courts (Jones, C. J, 2016).

Alternately, most states have statutes governing advanced health care directives. Even though states may set up the manner in which they enforce advance healthcare directives, land/or living wills differently, the effect is quite similar. States may recommend some forms and require others. Some statutes provide a template for advanced healthcare directives (Jones, C. J, 2016).

The contents of the form is defined by its nature and will specifically include language specifying its intent. Generally, advanced health care directives will state when it will apply—for example, it should state the patient’s wishes based on certain scenarios and what the patient exactly means (Jones, C. J, 2016).

Advanced health care directives that are comprehensive, provide a section for a patient’s religious beliefs. But they do not necessarily provide for an in depth discussion on how a patient’s religious belief dictates how they should be treated at the end of life. This becomes important where the religious patient is allowing their faith in God to drive their treatment, thus, theoretically making for less confusion at the bedside when the patients has laid out these desires in advance. Anything less may threaten a patient’s autonomy and result in unethical hospital practices (McCormick, T, n.d.).

In an article written by Kirchner (2005), she argued the advanced healthcare directive is not enough because changes in thoughts and values can occur in an otherwise healthy brain, but if that brain becomes injured, then these desires may change and no longer reflect the desires the patient had when they were healthy. While this may be true, for the religious patient that has family or even personal clergy who is aware of their religious desires on terms of end of life care, patient autonomy does not have to be interrupted since their desires can be sought through these means.

Conclusion

Hospital ethics and concerns for acting in an ethical fashion at all times is important to the field of healthcare because ethics has been described as beginning where the law ends. (McCormick, T, n.d.). Additionally, potential legal actions against health care providers and/or hospitals can be brought for injuries resulting from healthcare where lack of informed consent or violation of the standard of care is involved (McCormick, T, n.d.).

When a religious patient’s autonomy is not respected by hospitals and protocols are followed to the contrary of the patient’s wished, this can not only be deemed an unethical practice, but also as the hospital acting with informed consent of the patient. Lack of informed consent can be

raised where an end of life patient's religious views conflict with hospital protocols directing their treatment. In the 1990 case of *Cruzan v. MO Department of Health*, court held that family members would be allowed to make the same decisions regarding the refusal of medical treatment, including life sustaining treatments, for patients who lacked life sustaining capacity as long as they could establish clear and convincing evidence of the patient's previous requests or wishes (Jones, C. J, 2016). Along this same line of reasoning, family members should be able to effectively advocate a patient's autonomy, where that patient has lost capacity and had an advanced health care directive on file, has capacity and has an advanced health care directive on file, but as a result of the disease has lost the ability to effectively communicate, or neither has an advanced healthcare directive on file or has capacity, but the family can provide by clear and convincing evidence the wishes of the patient.

Brett and Jersild (2003) provide that when clinicians believe that an intervention is medically inappropriate or inhumane, they are not necessarily obligated to provide it simply because it is demanded on religious grounds. Instead, they propose that clinicians—preferably assisted by chaplains or clergy—should discuss alternative religious interpretations with the patient or family, and should attempt to reach a consensus on the appropriate limits to life-sustaining treatment.

Contrarily, it could be argued that the lack of an obligation to comply with religious beliefs, introduces a nonconformity to the patient's autonomy by the hospital, which also begs the question of why a patient's religious affiliation is even required to be entered in the chart if it has no true bearing on the patient's autonomy and the overall medical treatment relationship. Instead of stopping at the mere listing of the patient's religious affiliation, why not go further into how their religion influences their definition of end of life, which inevitably leads to preserving patient autonomy. Having a thorough understanding of this early on—instead of while the patient is on their death bed no longer able to speak or effectively communicate--can result in better use of financial resources on the hospital's part and reduce the feeling of pressure or accusations of illegality of unethical actions on the patient's part. One means by which this may be effected is through a mediation with the family of the patient and the medical team before the patient reaches the "critical" stage so as to reduce the evidence of unethical practices or pressure when the time arises where the evidence of "end-of-life" becomes pertinent. Religious leaders can also assist in helping hospitals understand the principles of the religion as they relate and pertain to how to preserve patient's autonomy regarding treatment at the end of life stage. (Jones, C. J, 2016).

Yee (2007) proposes that mandatory mediation is the extra dose needed to cure the medical malpractice crisis. This can also be used when ethical dilemmas exist in treating end of life patients.

This can be worked into treatment protocols for patients who have critical illnesses. If the autonomy is preserved through palliative care treatment of those religious patients who desire the discontinuance of life saving treatments, then likewise the autonomy should be preserved for those religious patients desiring that everything be done possible to preserve their lives, in accordance with the laws of their religion, even if it means they will suffer. Additionally, a more detailed section on religious beliefs regarding end of life can be added to Advanced Health Care Directives provided through both hospitals and outside attorneys. In both situations a patient's

autonomy will be better protected and the existence of unethical practices—whether intentional or unintentional--at the end of a religious patient's life will substantially decrease.

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