Torture or Treatment: A Case Study

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Abstract

Recent advances in medical technology provide medical teams tremendous tools to treat patients, however, when used inappropriately, these same advances become instruments of torture. The balance between torture and treatment in 21st-century medical care presents many complex moral questions surrounding the clinical care of a patient. These challenges are highlighted in the case of Mary, a 50-year-old woman with Down's Syndrome who only has the mental capacity of a three-year-old. Mary was admitted to a Catholic hospital with a post Harrington-rod replacement surgery infection. Her health rapidly deteriorated resulting in her being confined to the ICU for over 200 days. Mary's surrogate decision makers have not given up hope and believe against all medical odds that Mary will recover to a condition where she will be able to be discharged home. The medical team, on the other hand, believes recovery for Mary is not possible and while they are comfortable continuing her current care they refuse to provide any further life-sustaining treatment because they believe that treatment will be tantamount to torture. Ultimately Mary's surrogates and healthcare team find themselves at odds over the age-old question of torture or treatment. A path through this moral impasse begins to emerge when the five-box method, which considers the medical indications, patient preferences, quality of life, contextual features and the Catholic context, is applied.

Table of Contents

Appendices

Introduction

For over 2,500 years, since at least the time of the Greek physician Hippocrates, physicians have faced the question of treatment or torture. They have been forced to evaluate how to best approach a situation in which a patient requests a particular treatment that in their professional judgment is tantamount to torture. Today, with advances in medicine, this question is occurring much more frequently and becoming much more complex.

Over the past 50 years, the field of medicine has advanced exponentially. With this advance, the art of dying is becoming more complex. Whereas in previous generations a person seemed to simply pass away, today many people die connected to ventilators, dialysis machines, endotracheal tubes, or other medical technologies. While these advances in medical care have the capacity to help patients with curable conditions recover, these new technologies and medications are often used to keep patients alive for as long as possible even when there is no hope of recovery. In the face of these advances, the US Conference of Catholic Bishops (2009) warns that these developments "can either be an opportunity for genuine advancement in human culture or it can lead to policies and actions that are contrary to the true dignity and vocation of the human person" (p.8).

The balance between torture and treatment in the 21st century often leaves family members and medical teams facing complex moral questions surrounding the care of a patient facing a life-threatening condition. These complex questions have caused medical ethicists to ponder what it means for a treatment to be futile. Even after decades of debate, medical ethicists have been unable to provide a suitable futility standard. Following an extensive study of the futility debate, Moore (2017) properly acknowledges "as an inherently subjective classification, the authors argued, designating treatment as futile does not resolve disputes between patients and physicians over aggressive end-of-life care" (p.454).

As the debate over medical futility wages on, families and clinicians find themselves facing very serious ethical questions for which they don't have the luxury of waiting for the academics to agree on the futility debate. On a daily basis they have to answer the question 'is the proposed course of action torture or treatment?' This paper seeks to sidestep the futility argument in order to practically demonstrate how questions of torture or treatment can be resolved in a Catholic clinical setting by applying the Five-Box method put forth by Marugg, Atkinson, & Fernandes (2014) to a case study.

The Case

Mary is a 50-year-old woman with Down's Syndrome who only has the mental capacity of a three-year-old. She has three brothers: Rob, John, and Tom. Tom and John serve as her court-appointed co-guardians. Until recently she lived in a group home but moved into Tom's house when she could no longer walk due to back problems that arose from scoliosis.

To resolve the scoliosis, a Harrington Rod replacement surgery was performed at another hospital in December. After the surgery, Mary contracted an infection and was admitted to a different Catholic hospital. The physicians at the new hospital removed the Harrington rods with the hope of removing the source of the infection.

Mary had been hospitalized for nearly eight months and had spent most of her hospitalization in the intensive care unit (ICU). For most of her stay in the ICU, Mary remained on a vacuum-assisted closure (VAC), she was primarily ventilator-dependent, suffered extensively due to acute renal failure necessitating continuous renal replacement therapy (CRRT), and she was receiving Levophed for months to help resolve her hypotension. Mary frequently grimaced and appeared to be in pain, but Tom refused to allow Mary to receive pain medications that had sedating effects.

While Mary continued to languish in the ICU, the medical team and Mary’s family remained unable to agree on the ethical course of treatment. Mary’s family wanted to do everything possible to bring her home. Tom agreed to take early retirement so that he could care for her on a home ventilator and he believed that he could take her to receive her weekly hemodialysis treatments she needed for her acute renal failure. Meanwhile, the critical care attending physician did not believe Mary would become stable enough to be discharged and therefore recommended that Mary’s code status be changed to reflect the desire to provide no further life-sustaining treatment.

This disagreement over treatment led to a hostile relationship between Mary’s family and the medical team. Mary’s brother Tom, frequently lashed out at the nursing staff, lodged complaints with the state, wrote a letter to the diocesan bishop to accuse the hospital of having a culture of death, and even called the police to accuse the hospital of assault. Even after a meeting with the diocesan vicar for moral matters in healthcare and biotechnology, the hospital’s ethicist and the director of pastoral services, who all agreed that foregoing further life-sustaining treatment, including cardiopulmonary resuscitation (CPR), was a moral choice, Tom believed that the decision to forgo CPR was a decision to kill his sister.

By mid-August, Mary’s condition improved to the point that the Levophed was decreased, she was removed from CRRT for nearly 36 hours, was able to use a trachea collar for four to six hours a day, and was able to spend time out of her bed in a chair. Sadly, the progress did not last long and she quickly coded. Following the code, the critical care attending physician determined that it was most likely not possible to wean Mary off the ventilator. This belief was confirmed after increasing the ventilator assistance leading to the removal of some CO_2 which resulted in Mary becoming much more responsive.

Presently, Mary recognizes some people and is responsive enough to move her head, hold out her hand to people she knows, and at times she can communicate non-verbally with her brothers. Though currently stable, she cannot be discharged until her hypotension can be managed. Without any hope of Mary being discharged in the near future, and with the concern that her condition may regress, or that she may once again code, the medical team finds themselves at an impasse. They believe any further life-sustaining treatment would only serve as torture to Mary, but Mary's family believes that failing to provide any form of life-sustaining treatment would be unethical. The medical team and Mary's family find themselves at the age-old question: treatment or torture.

The Five – Box Method

The complexity of modern medicine often means that critical care patients like Mary, have numerous factors that must be analyzed when determining the ethics behind a particular course of action. This process of discerning if a medical procedure is torture or treatment requires the clinician to sort through many different factors in order to identify, analyze and resolve the ethical issues surrounding each particular case. To help organize these different issues Jonsen, Siegler and Winslade (1998) introduced their four-box method as a tool to help clinicians find "a straightforward way to sort the facts and values of the case at hand into an orderly way that will facilitate the discussion and resolution of the ethical problem" (Johnson, Siegler and Winslade, 1998, p. 2).

The four-box method proposes that every clinical case should be evaluated by means of four key topics: medical indications, patient preferences, quality of life, and contextual features. They argue that these topics not only organize the many facts of the particular case, but also highlight the moral principles, which are relevant to each case (Johnson, Siegler and Winslade, 1998).

The first topic, medical indications, addresses the diagnosis and treatment of the patient's medical condition. This box seeks to evaluate what medical treatment possibilities exist in light of the patient's condition. Rather than just stopping at the medical facts, this box seeks to describe both the purpose and the goals of the medical interventions. This evaluation serves to help the clinician focus on discovering what is good for the patient and what potential harm the patient should avoid.

After discerning the different possible medical interventions, the clinician should consider the second principle: the patient's preferences. This second box seeks to respect the autonomy of the patient by discerning her own values and her assessment of the benefits and burdens that could result from each particular treatment. Here the clinician must make sure he understands the patient's wishes while also ensuring that the patient sufficiently comprehends her situation and is making decisions of her own free accord. In situations like Mary's, in which the patient cannot decide for themselves, this box also considers who has the authority to make decisions on behalf of the patient and what the limits of that authority are.

Having identified the possible medical approaches and the preferences of the patient, the third box seeks to evaluate how the treatment or lack of treatment will affect the quality of life for the patient. This demands that the clinician evaluate what the patient understands to be quality of life and then take that quality of life judgment into consideration when considering the ethical judgments at hand. While this judgment is subject to bias, an honest undertaking of this question will help bring many different ethical issues to the surface.

Lastly, the analysis of a particular case cannot forget the reality that the specific patient does not stand in isolation. Rather every case is linked to a larger community of people, institutions, financial, legal, and social arrangements. The fourth box undertakes the critical attempt to evaluate the specific case in light of the larger community.

While the four-box method does a good job of organizing the secular issues surrounding a particular case, Catholic healthcare institutions cannot leave their faith at the door and must also consider the Catholic moral tradition. To help integrate the Church’s teachings, Marugg, Atkinson, and Fernandes (2014) added a fifth box to the traditional four-box method that integrates the principles of Catholic social and ethical teaching. This box makes use of the Church’s wisdom to “form a correct conscience based on the moral norms for proper health care” (US Conference of Catholic Bishops, 2009, 9).

When faced with a question of whether further medical care is treatment or torture, it is essential for the clinician to take the time to organize the many different holistic elements of care for the patient. While the five-box method of ethical decision-making is not a step-by-step guide to determining the ethical means of acting, it is a helpful organizational tool which assists clinicians in organizing the details of a case so that a proper ethical decision can be made. The five-box method is a helpful tool which assists clinicians in stepping back from their own opinions to objectively evaluate the medical facts of the case, the preference of the patient, the quality of life for the patient, other factors to ensure justice and fairness are being upheld, and insights from the Catholic moral tradition are being applied.

Medical Indications

Mary was initially admitted to the hospital on January 11th for an infection she contracted after a Harrington rod replacement surgery. Her health rapidly deteriorated and her medical care became very complex. For nearly eight months Mary was confined to the ICU, primarily battling renal failure and respiratory failure. In an attempt to rehabilitate Mary to a condition where she could be discharged to Tom’s house, her care was accelerated in early August.

By the middle of August, it appeared that Mary was making significant progress. She was able to use a trachea collar for six to ten hours at a time, her Levophed was decreased, she was off CRRT for about 36 hours, and was even sitting up in a chair. Sadly, this push in treatment caused her to code on August 22nd. Following the code, she was assessed to have 60% dead lung space. Once the ventilator settings were increased and CO_2 was removed Mary returned to a more responsive state.

The physicians were primarily concerned about renal failure. They were also concerned about respiratory failure, continued hypotension, the need for continued ventilator-assisted breathing, and pain management. While the medical team acknowledged Tom’s desire to have Mary discharged to his house and were willing to try to make that possible, they believed that her best chance to be discharged from the hospital would be to go to a Long-Term Acute Care (LTAC) center. According to Stefanacci’s (2015) standards, if Mary’s hypotension could be stabilized she could meet the requirements for admission to a LTAC center. While at the LTAC center they could continue the attempts to wean her off of the ventilator and possibly even work towards discharging her to Tom’s house.

Hypotension

In an attempt to discharge Mary from the ICU, the physicians focused on her hypotension. They proposed three medical treatment options for Mary's hypotension. For most of her time in the ICU, they had managed her low blood pressure with Levophed. Levophed is a potent vasoconstrictor and inotrope, that is administered via continuous IV infusion to control acute hypotensive states. (Levophed, 2018) Shortly before Mary coded, the physicians agreed to switch her to ProAmatine, a vasopressor administered in tablet form to control hypertension that is primarily prescribed for patients who are still impaired despite standard clinical care (Proamatine (Midodrine Hydrochloride): Side Effects, Interactions, Warning, Dosage & Uses, 2018). Immediately after coding, Mary was placed on Dopamine, a sympathomimetic amine vasopressor, administered via continuous IV infusion to correct hemodynamic imbalances, because Dopamine has a greater cardiac boost and the capacity to stabilize blood pressure. (Dopamine, 2018) While the Dopamine proved effective for managing Mary's hypotension, Lauschke, Teichgraber, Eckardt (2006) demonstrated that "low-dose dopamine can worsen renal perfusion in patients with ARF" (p. 1669). In the balancing act of caring for Mary, her renal health had been sacrificed in order to keep her pressure stable.

Renal Failure

Acute renal failure became the primary health concern for Mary. Currently, there are three different available renal replacement therapies potentially available to her. The three therapies are peritoneal dialysis (PD), intermittent hemodialysis (HD), and continuous renal replacement therapies (CRRT). Despite the various advances in renal therapies, the mortality rate for acute renal failure remains over 50% (Pannu & Gibney, 2005).

For most of her hospitalization, Mary was provided with CRRT: a renal replacement therapy that is applied continuously in the ICU. By providing continued replacement therapy with CRRT, a slower and more stable clearance than PD or HD is supplied (Pannu & Gibney, 2005). In an attempt to discharge Mary, the physicians tried to change her treatment to either PD or HD.

As the medical team considered discharge options for Mary they initially considered ordering hemodialysis for Mary. Hemodialysis is an intermittent dialysis that patients usually receive for three to six hours three times each week (Pannu & Gibney, 2005). They believed that HD would provide Mary with the best possible care if she could be discharged to a LTAC center.

Tom's desire to bring Mary home gave the physicians reason to consider peritoneal dialysis. While PD is used only in limited circumstances it could be administered at home with a trained family member. This option would prevent Mary from being exposed to the many risks that are associated with being transported to an outpatient dialysis center three times each week. However, PD is not completely without its risks. In addition to requiring the surgical insertion of a catheter into the peritoneal cavity, this catheter frequently leaks or malfunctions (Pannu & Gibney, 2005).

After Mary coded, CRRT was continued because the doctors believe her hemodynamic instability made it impossible for Mary to receive either HD or PD. Experience has shown that when Mary was switched to HD, the dialysis caused her blood pressure to drop. As her care continues, she will need to either switch to HD or PD if there is going to be any hope of her being discharged either to a LTAC center or to Tom's house.

Respiratory Failure

While Mary’s low blood pressure and her necessity for CRRT are keeping her from being discharged to a LTAC center, she also remains ventilator dependent. Shortly before she coded, she had been weaned to a trachea collar for six to ten hours a day but is now completely ventilator dependent. Mary could be discharged to a LTAC on a ventilator but if she is going to be discharged to Tom’s house she will need to be on a home ventilator.

If Mary is going to remain on long-term mechanical ventilation, Tom’s house is certainly the preferred location for Mary. In addition to extreme cost savings, freeing ICU beds for other seriously ill patients, and protecting Mary from hospital-borne infections, the home ventilator care will greatly enhance her quality of life by allowing her to reintegrate with her family and the greater community (King, 2012).

While a home ventilator is preferable, the doctors do not believe, following her code, that Mary could be weaned to a home vent system. Following the code, tests indicate that she has 60% of dead space in her lungs. As her ventilator settings are increased and additional CO_2 is removed, Mary has become much more responsive. Despite the decreased lung capacity and increased functionality on the ventilator, Tom refused to accept the determination from the physicians that Mary must remain ventilator dependent for the rest of her life.

In an attempt to have Mary discharged, Tom has requested that he be allowed to wean Mary off the ventilator from his house. Weaning, in this sense, is simply the process of removing the patient from a ventilator. While patients whose underlying disorder has been stabilized can be discharged from the ICU, the complexities of weaning a patient from a ventilator require expert care that can only be supplied in a clinical setting (Navalesi, et al., 2014).

Infection

Infection was the primary cause of Mary’s rapid decline. Following evidence that suggests “instrumentation removal and primary wound closure are reliably curative” (Muschik, Lück, & Schlenzka, 2004, 650) the physicians decided to remove the Harrington rods. Since the removal of the Harrington rods and subsequent wound care, Mary’s infection seems to be under control.

Pain Management

Mary is receiving numerous treatments that inflict substantial pain on her body. She has indicated by pointing that she suffers pain related to her legs, her trachea, NG tube, and her abdomen. As Blumenstein, Shastri, & Stein (2014) note, abdominal pain is a common symptom of PEG feedings. Additionally, the use of opioids with patients receiving CRRT presents the challenge of balancing pain control accompanied by the risk of side effects that include respiratory depression, hypotension, and central nervous system toxicity (Johnson, 2017).

While pain medication is administered to Mary, she still frequently grimaces and appears to be in pain. At times, the physicians have requested stronger pain medication, but Tom refuses to consent to any pain medication that would have sedative effects. At one point, doctors wanted to administer Fentanyl, a narcotic strength intravenous anesthetic, however, Tom would only consent after all other means of reducing pain were exhausted.

Conclusion

After spending over 200 days in the ICU, Mary’s body has become very worn down. In the interest of trying to save her life and give her some hope of being discharged, her care has become very complex. These multifaceted and frequently changing treatments have raised many problems that must be solved. As care continues for Mary, Tom and John will have to make decisions for her after discerning what is truly in her best interest.

Patient Preference

With only the mental capacity of a 3-year-old, Mary cannot make health care decisions for herself nor does she have the capacity to fully provide consent to specific medical treatments. The American Medical Association (2016) dictates that “when a patient lacks decision-making capacity, the physicians have an ethical responsibility to… identify an appropriate surrogate to make decisions on the patient’s behalf” (p.2). In this case, Mary’s brothers Tom and John have already been named as Mary’s legal guardians. As Mary’s legal guardians, Tom and John share the responsibility for making medical decisions for Mary.

Rather than seek his own desires, a surrogate must seek to act on behalf of the patient. He must place his own opinions to the side and make decisions based on what the patient would have chosen if she were competent to do so. Pope (2012) argues that when a surrogate is trying to determine the choice that an incapacitated patient would make for herself, he should follow a three-step hierarchy. First, he should consider the expressed wishes of the patient, then progress to a substituted judgment, before finally settling for the best interest of the patient.

The principle of expressed wishes demands that if the patient, before she became incompetent, spoke directly about the type of treatment that she would have liked to receive in the particular situation she finds herself in then her wishes should be honored. If, however, the patient did not leave concrete instructions, the surrogate, taking into account the personal values and beliefs of the patient, must then try to make a decision that most closely conforms to the decision that the patient would have made under the circumstances. If the preferences of the patient cannot be discerned, then the surrogate must make the decision that is in the best interest of the well-being of the patient. (Pope, 2012).

Since Mary has been mentally incapacitated for her whole life she has never been able to make any substantial decisions about how she wishes to be treated and she is also unable to have a set of personal values from which to make decisions. Due to Mary's mental illness, Tom and John are left with making decisions they believe are in the best interest of Mary. Yet simply because Mary needs someone to make medical decisions on her behalf, and despite the fact that the law has made Tom and John her guardians, they should not be free to simply command whatever they want.

Methods of Decision Making For Those Who Have Never Been Competent

Rather than rely on their own personal opinions, Tom and John first must find an objective framework within which to make decisions about what is truly good for Mary. The philosopher Erike-Henner Kluge (2008) argues that there are five different potential models for ethical decision making that are that are available for a surrogate to employ on behalf of a patient who has never been competent to make decisions for herself. These five models are medical appropriateness, familial values, beneficence, substituted judgment, and doing everything that is possible.

The first model, the 'medical appropriateness model,' calls for the surrogate to make decisions based on what is most medically appropriate. This model seeks to make a decision based on what will lead to the most clinically successful outcome. While the clinical insight is important, the medical facts cannot be separated from the personal values. Competent patients frequently make ethical decisions to forgo certain treatments, which could be medically successful because they determine that the treatment would be too great of a burden. For example, it may be medically possible to keep Mary alive for another 50 years in a manner that is extremely painful. While medically successful, it is likely that if given the choice many competent patients would choose to forgo the treatment. If the medically appropriate standard is not binding on a competent person, then it cannot in justice be binding on an incompetent patient.

The ‘familial values model’ is grounded in a belief that family members share similar values and so the incompetent person would most probably desire the same treatment as a surrogate who is from the same family. While one’s family does influence a person’s core values to a certain extent, competent people frequently disagree with their family members about certain values. For example, Ganzini, Beer, & Brouns (2006) show that only 51% of Oregon family members would support a patient if she requested physician-assisted suicide (p. 232). In other words, 49% of Oregon family members would not share the value of physician-assisted suicide with a member of their family. Even when family members do share a particular value, the fact that they share a particular value does not mean it is an ethical value. The Neo-Hittite state of Carchemish, for example, believed in castration for regents to their underage heirs to the throne (Bryce, 2012). Yet simply because the royal family shared a belief in castration does not make castration an ethical value. While family values do have a limited role to play in surrogate decision-making, they cannot be considered the sole determining factor.

The ‘model of beneficence’ calls for the surrogate decision maker to do what is good for the patient. Yet, unlike the medically appropriate model, beneficence is not an objective concept because it rests on the surrogate’s belief about what it means to truly be a human person. As Kluge (2008) rightly points out, this model simply replaces family values or the opinion of the doctor with someone else's opinion about what is considered the best interest of the patient.

The ‘substituted model’ attempts to rectify the biases of the first three models by encouraging the surrogate to make the decision that the incompetent patient would have made if she were able to exercise her values. While this model acknowledges the uniqueness of the patient, this position practically collapses onto itself. It is simply impossible to even begin to imagine what values the incompetent patient would employ in order to make a decision if they could because the patient has never and will never be able to make a competent decision.

The do ‘everything possible model’ attempts to remove all subjective elements of the decision-making by demanding that the surrogate order anything which can be done to be done. Yet, Rothman, Ness, O’Leary & Fried (2007) discovered that patients with chronic diseases frequently refuse medical and surgical interventions beyond medications. In essence, this model discriminates against the incompetent patient by binding them to receive care that a competent person would refuse.

While each of these models has their flaws, Kluge (2008) recognizes some merit in each of them. He argues that both the subjective and objective elements of decision-making contained in these models can be combined into a two-part standard. The first standard demands that the subjective values used by the surrogate be in conformity with principles that demonstrate a respect for the human person. The second standard demands that the objective values do not deprive the patient of the same opportunity for development that is afforded to other members of society. This double standard serves to protect the incompetent patient from being discriminated against while also protecting the surrogate from making demands that cannot be fulfilled. As Tom and John make decisions for Mary, they must weigh the objective medical facts with the subjective facts of what they believe is best for Mary.

Mary’s input

While Mary has never been legally competent and does not have the capacity to make her own choices, she appears to have some capacity to express insights, which should be considered.

The reality that Mary does not have the mental capacity to understand totally what is going on should not completely disqualify her from the decision-making process. Rather, what she can understand must be respected and included in decisions about her medical care.

The first step in making surrogate decisions demands that John and Tom understand what Mary understands. Mary demonstrates a limited capacity to recognize individuals. For example, when the ethicist came by to visit and introduced herself as the one who shares a birthday with her, Mary opened her eyes, turned her head and held out her hand to wave at her. Mary also has the capacity to communicate with family members through nonverbal manners. She also has the capacity to point at parts of her body that are affected by paralysis or catheters. This ability to recognize others and indicate pain demands that Tom and John seek Mary's input about her comfort level. Simple questions like asking Mary to point to areas of discomfort can help John and Tom identify Mary's interests in her care.

Tom and John's Capacity to Make Decisions

Tom and John's role as the surrogate decision-makers for Mary requires a delicate balance between the objective medical realities and subjective patient preferences. This balancing act is very difficult because Zier, Sottile, Hon, Weissfield & White (2012) found that there are both cognitive and psychological factors that contribute to the optimistic expectations of grim medical prognosis that surrogates often face. Beyond a simple lack of understanding, surrogates can mistrust the ability of physicians to make a prognosis and they can interpret prognosis in an overly positive way as a means of coping with the grim realities.

Batteaux, Ferguson, and Tunney (2017) found that surrogate decision makers tend to make different decisions for the person for whom they are a surrogate for than they would for themselves. They further found that a surrogate is more likely to be affected by the outcome of their decision if they are making a decision for a friend than if they are making a decision for a stranger. This naturally brings a certain handicap to the person making the decision. While this handicap can be overcome when the surrogate is able to step back and make decisions from the outside, Tom and John, bring a strong bias to the table. This makes it difficult for them to step back far enough to make rational choices.

While Tom and John want to do what is best for Mary, they have serious conflicts of interest. First, they have a deep-seated distrust of the healthcare system because their mother died of an unrecognized drug interaction while living with Tom. This lack of trust in the healthcare system has led them to believe the healthcare team is trying to kill their sister. This deep-seated distrust can lead Tom and John to ignore the essential objective information being presented to them by the medical team and can cause them to make decisions based only on their own subjective biases. Additionally, Tom and John regret that they put Mary through the Harrington Rod surgery, which led to her infection and current prognosis. This feeling of guilt is a strong impetus for them to want to try everything to rectify the situation. When this is coupled with the reality that Tom made a promise to Mary that he would bring her back home, Tom and John find themselves paralyzed and unable to accept any prognosis that will not allow Mary to be discharged to Tom’s house.

Conclusion

Mary finds herself in a precarious situation. She is able to express some limited insights into her treatment, but she is unable to make her own choices. Mary is dependent on her two brothers, who both bring serious biases towards her care.

Tom and John are clear: they want to Mary to be rehabilitated to a place where she can be discharged to live with Tom. While Tom and John have made their preference clear, these preferences must be understood in light of their strong biases. This bias could prevent Mary from receiving treatment that is objectively best for her and subjectively respects her dignity as a human person. Tom and John’s expressed preference for Mary must then be approached in light of Mary’s quality of life.

Quality of Life

For most of history, medical treatment decisions have been made by physicians who weighed the effectiveness of a specific treatment. As a purely objective determination about medical outcomes, it was reasonable to leave healthcare decisions in the hands of the physicians. In 1946, however, the introduction of the Constitution of the World Health Organization formally recognized that health care includes not just one's physical health, but also their mental health and other social dimensions (Constitution of the World Health Organization, 1946). This shift in the understanding of healthcare introduced subjective elements to healthcare decision-making. Since 1946, the role of the physician has slowly evolved in such a way that today the job of the physician is "to focus on patients' lives rather than patients' bodies" (Sullivan, 2003, p. 56).

This shift towards a holistic understanding of the importance of quality of life is rooted in the recognition that every dimension of the human person: physical, psychological, spiritual and moral, must be promoted in harmony. It recognizes that health should "be safeguarded and looked after as the physical-psychological and spiritual balance of the human being" (John Paul II, 2005). Healthcare decisions require a balanced integration of what is medically possible with what respects the dignity of the individual human person.

Tom and John have made the determination that everything medically possible should be done for Mary. In making this determination, they failed to accept the inevitability of death and ran the risk of violating Mary's human dignity. After all, a proper respect for the dignity of the human person recognizes that life is not an end in and of itself. Since there is more to life than the physical good of a patient, there should be recourse for a patient, or her surrogate, to refuse a treatment that comes with a serious risk or extra suffering unless it can be reasonably concluded that there is a proportionate benefit (US Conference of Catholic Bishops, 2009).

Rather than insisting that every medical possibility be attempted, John and Tom need to step back and make decisions based not simply on medicine but on what truly respects Mary's dignity as a human person. They must evaluate what effect the treatment Mary has been receiving is having on the whole of her individual person. While neither the medical team nor Tom and John are suggesting that Mary be forced to die, Tom and John must seriously evaluate the possibility to changing Mary's code status to allow her to die if her condition worsens again.

Mary's Past Quality of Life

Prior to Mary's Harrington Rod Replacement surgery, there was every indication that Mary valued her life. While she had a very limited mental capacity she was able to live in a group home and interact with others, including her family who loved her dearly. Mary certainly experienced many different challenges as a result of her Down syndrome, but there is overwhelming evidence to suggest that many people with Down syndrome value their life (NDSS, 2017). In fact, Natalie Dedreux, an 18-year-old with Down syndrome from Cologne questioned Chancellor Merkel about Germany's policy allowing abortion for those diagnosed with Down syndrome by exclaiming "I don't want to be aborted, I want to be born" (Teen with Down Syndrome puts Merkel on the spot over abortions, 2017). Even with her many serious handicaps, Mary found pleasure in the simple things of life. She enjoyed sitting in front of the TV, eating, and playing with her money.

As Mary's scoliosis worsened, she was no longer able to move about as she used to and could no longer live in her group home. Attempting to return her to better physical health and hopefully return her to a group home, Tom and John had Mary undergo a Harrington Rod replacement surgery. Mariconda, Galasso, Barca, & Milano (2005) found that patients who have undergone this surgery have reported long-lasting satisfaction with its outcome. Unfortunately, Tom and John's desire to improve Mary's quality of life led to an infection and a much worse quality of life.

Mary's Current Quality of Life

Currently, Mary finds herself in critical, but stable, condition. As long as her ventilator settings remain high, she continues on CRRT, receives her Dopamine regime, and remains on artificial nutrition and hydration, she is medically stable and capable of having interactions with others, enjoying her television shows, and playing with her money. While Mary can enjoy some of her previous comforts, she is still bedridden and appears to be in significant pain.

Given the treatment that Mary is receiving, the physicians seem to be doing more *to* Mary than *for* Mary. Every medical decision Tom and John are making for Mary is made based on an attempt to simply preserve her life with the hope that she will be able to make a full recovery; a hope that the medical team has clearly articulated cannot happen. While a person must use ordinary means to preserve their life, they are not obligated to undergo procedures that do not provide a hope of benefit without imposing serious risks or burdens to the patient. (US Conference of Catholic Bishops, 2009).

When determining what care Mary should receive, Tom and John must first evaluate if the treatment really does offer some hope of benefit. As Wildes (1996) rightly notes, "this hope of benefit must be more than simply the hope of postponing the inevitable" (p. 505). Since a treatment can only be considered obligatory if there is some hope of benefit to the health of the patient, Tom and John must first evaluate if Mary's ventilator and CRRT treatments really have a benefit for her health.

Mary's Future Quality of Life

The attempts in early August to restore Mary's quality of life through weaning her from the ventilator, removing CRRT, and switching to a more manageable blood pressure medicine almost killed her. After coding, the medical team does not believe it will be possible to remove her from any of her life-preserving treatments. While these treatments are keeping Mary alive and allowing her to maintain some level of dignity, they will not be able to keep her functioning forever.

The medical staff has requested that John and Tom change Mary's code status so that if she codes again they will not be forced to try to revive her. While John and Tom are against this plan, the medical staff believes Mary is vulnerable and given their medical knowledge of CPR, believe that performing CPR will violate her dignity because in Mary's case it is tantamount to torture and not treatment.

Contrary to popular belief, CPR is not a magical procedure that restores patients back to their original life. Cooper, Cooper, & Cooper (2006) found that the survival rate for in-hospital patients in need of CPR is only around 18%. Additionally, Larkin, Copes, Nathanson, & Kaye (2010) found that patients, like Mary, who have hypotension and are using vasopressors have a much higher mortality rate. In addition to the low success rate for CPR, the procedure often inflicts physical harm on the patient. Kralj, Podbregar, Kejzar, & Balazic (2015) demonstrated that 91% of females receiving CPR received a related skeletal chest injury. Forcing Mary to undergo CPR if she codes will only result in a low probability of survival, increased physical harm to her body, and a worse quality of life.

Since "true healing is to 'to make whole again' in the fullest sense" Tom and John need to recognize that "it is possible to heal even when the end of earthly life is unavoidable and imminent.” (Pellegrino, 1999, p. 77) Rather than focus on causing more harm to Mary, Tom and John should work with the medical team to keep her comfortable and allow her to enjoy the simple pleasures of her life. In the balance of ensuring a good quality of life for Mary, Tom and John should accept palliative care for Mary.

The American Medical Association (2017) defines palliative care as care “which relieves suffering and improves quality of life for people with serious illnesses, no matter whether they can be cured.” Palliative care makes use of an interdisciplinary team composed of a physician, nurse, social worker, and chaplain to address the medical, social, cultural, and spiritual needs that affect a patient facing a serious illness and their family. It seeks to create “a comprehensive non-curative plan for prevention and relief of pain and other forms of physical, psychosocial, and spiritual suffering by means of early identification, assessment, and intervention” (Hilliard, 2008, p. 3). It can be offered to a patient of any age who is at any stage of a serious illness and is intended to be provided concurrently with their other treatment.

Even though Tom and John have rejected hospice care for Mary, they should be open to palliative care, because while palliative care and hospice come from a similar background there are essential differences between them. While hospice care is available only to those people who have fewer than twelve months to live and have no desire to seek curative treatments nor potential to be cured, palliative care can be provided at any stage of a serious illness even while the patient continues to receive curative treatment. In fact, Henson (2012) found that “patients who received access to palliative care showed significant improvements in quality of life and mood.” (p. 809) Palliative care will assist Tom and John with the many challenges to come as they continue to provide Mary with life-sustaining medical treatment.

Conclusion

Mary has always found joy in her simple life. Sadly, her infection has left her dependent on life-sustaining treatments and the physicians believe that her health will only deteriorate. While Mary’s surrogates, Tom and John, want every treatment option available to be provided, some of these treatments, like CPR, could result in violating Mary’s dignity. When evaluating Mary’s quality of life and her future prognosis, the medical providers must heed the obligation asserted by Pope Francis (2016) to “assert the right to a natural death, without aggressive treatment and euthanasia” (Par. 83).

Contextual Features

The practice of modern medicine solidifies the need for interdisciplinary discourse in resolving ethical dilemmas. Nair-Collins (2015) rightly recognized that “health care is a collaborative social practice dependent on many professions and occupations” (p. 560). It is simply no longer possible for a physician to set a course of treatment without the input of the rest of the medical staff, the patient, or her surrogates.

The complexities of Mary’s situation require that many different specialists, each with their own perspective and insight, come to a consensus about the best way to treat her. If Mary is going to receive the care she deserves, everyone involved, both the individual members of the medical team and Mary’s surrogates, must come to an agreement about what the best course of treatment will be.

After Mary’s code, the medical team and Mary’s surrogates, find themselves at a moral impasse. Tom and John have become so fixated on returning Mary to her pre-surgery self that they have failed to understand that the physicians do not believe this is possible. The medical team, on the other hand, wants to do whatever they can to relieve Mary’s suffering without placing her under any more unnecessary burdens.

Since it is not possible to transfer Mary to another facility, the medical team and Mary’s surrogates must find a unified way to move forward. If the medical team and Mary’s surrogates are going to break through this moral impasse, the principles of justice and fairness must be examined. Only after a path has been forged through the moral impasse will the healthcare team be able to re-establish a healthy relationship with Tom and John. If there is any hope of restoring the patient – healthcare team relationship, the essence of this relationship must be properly understood, the obligations of the medical team must be articulated and the role of the institution must be defined.

Relationship

Tom and John’s strong insistence that every medical possibility be explored for Mary leaves the medical team in a precarious position. The medical team has a fundamental obligation to avoid doing “harm or injustice” to their patients (Greek Medicine - The Hippocratic Oath, 2012). As Paris, Cassem, Dec, & Reardon (1999) correctly dictate, “from the earliest Hippocratic tradition, two ethical principles guide the physician's role in medical treatment. The first is expressed negatively, namely, do not harm, the second is where possible, restore or maximize health” (p 43).

The medical team is in the business of healing patients or providing comfort to them when they cannot be healed, but the treatment Tom and John are requesting for Mary appears to have no hope of helping Mary recover, while instead inflicting more pain and suffering on her. The attending physician went so far as to express to the family that in his 13 years of experience, 99% of patients he had cared for in Mary’s situation would not want to go through what Mary went through and would not want to continue with that treatment for the rest of their lives. Tom and John’s insistence on caring for Mary at all costs has taken its toll on the medical staff who now feel that they are being forced to torture Mary instead of treating her.

For as much as Tom and John are focused on the health of their sister, they cannot overlook the fact that they also have an intimate relationship with the medical team who is accompanying them every step of the way. The medical team does not work independently from Mary, Tom, and John and vice versa. This symbiotic relationship imposes obligations on both the patient and the physician. Since it is wrong for someone to help another person harm herself or harm another person, neither the patient nor the medical team can be obligated to participate in a treatment that they believe will harm the patient. (Parker, 2011) Any attempt by the medical team to cooperate with Tom and John in doing something that harms Mary would violate not only their professional obligation but also the first principle of practical reason which states that "good is to be done and evil avoided" (ST I-II, Q94. Art 2, C).

Medical Team's Obligations

Cassel (1996) rightly exclaimed, "medicine is, at its center, a moral enterprise grounded in a covenant of trust" (p. 604). The word covenant comes from the Latin words *con* and *venire* and literally translates to *coming together*. It is a coming together of two or more parties, which comes with an obligation that binds one or both parties to certain duties (Hugenberger, 1994). In the realm of healthcare, this covenant relationship demands that the medical team uses their skill to ensure that they only provide treatments that will be beneficial or at least not harmful or burdensome.

From the moment the medical team first began to care for Mary, they entered into a covenant relationship with her. Since Mary is totally dependent on those who care for her, her relationship with the medical team "is of its nature an unequal relationship built on vulnerability and promise" (Pellegrino, 2006, p. 67). The covenant then imposes a moral obligation on the medical team to only provide those treatments which they believe will be beneficial or at least non-burdensome.

Just as Tom and John are moral agents responsible for their actions, each member of the medical team is also a moral agent responsible for their actions. While the patient or her surrogate have the "right to exercise self-determination in making personal and informed choices … Both the patient and the physician have the right of autonomy" (Clark & Mikus, 2000, p.28).

The medical team has an obligation to allow the patient, or her surrogate, to choose the best course of action from medically acceptable treatment options, but they do not have an obligation to offer treatments that in their judgment are counter-therapeutic (Moore, 2007). A proper respect for the autonomy of the medical staff demands that patients not demand a member of the medical team override their values.

The right to self-determination does not give a patient or her surrogate the right to choose anything they want. Rather, true autonomy is rooted in the truth. For as Sarah, Diat, & Miller, (2015) rightly warns, “liberty without truth is deceitful; the absence of a moral connection between liberty and truth can only produce a form of anarchy” (p. 184). Authentic freedom is not the ability to do what we want, but rather the ability to do what we should do. (John Paul II, 1995)

Tom and John must recognize that the primary covenant relationship is between the medical team and Mary. The covenant relationship only involves the surrogates indirectly because they make decisions on behalf of the patient. When a surrogate is responsible for the medical decision-making, the covenant between the patient and the medical team further implies that the medical team has “a fiduciary responsibility to the patient to assure that the surrogate has appropriate care and concern” (Nair-Collins, 2015, p. 574). This fiduciary responsibility demands that if the medical team truly believes that the surrogate is making an inappropriate decision that would lead to significant harm to the patient without any hope of benefit, the medical team must investigate further, consult with other experts, and potentially find a means to override the surrogate’s decision. (Nair-Collins, p. 2015)

Futility Policies

When medical teams and patients or their surrogates find themselves at a moral impasse the healthcare institution must find a way to balance the autonomy of the patient and the autonomy of the medical team to break that impasse. As Capone and Grimstad (2014) rightly recognize, while “the patient has the right to make their own determination about the best treatment option, patients cannot be permitted to choose an immoral option” (p. 621). A physician should not be forced to provide a treatment that they believe is excessive because that would reduce “the physician from a professional and moral agent to a servant of the patient’s demands” (Moore, 2007, p. 458). While the physician should not be reduced to a servant who must obey every demand of a patient, he should also not have the option to unilaterally refuse treatment. The simple refusal of treatment by a physician violates the patient’s right to autonomy without due process and runs the risk of allowing the physician to make a mistake in judgment with consequences for the life of the patient that cannot be reversed (Moore, 2007). Since neither the medical team nor the patient or her surrogate should have sole recourse to make a treatment decision that one party disagrees with, the institution must be prepared to step in when disagreements arise.

In an attempt to protect the autonomy of physicians while also respecting the rights of the patient, the American Medical Association (2008) calls for every healthcare institution to adopt a seven-step medical futility policy. This policy seeks to bring the patient and medical team into alignment about the best course of treatment and when that cannot be done, it seeks to find another provider who will provide the care requested for the patient, or provide due process for the refusal of treatment if no other provider will offer the care. First, the patient, or her proxy, along with the physicians should seek to understand what is truly futile care for the patient and they should seek to come to a joint decision. If they are unable to resolve their differences, additional consulters should be brought into the process to try and reach a consensus between the patient or her surrogate and the medical team. If the differences cannot be reconciled, the institutional review committee should evaluate the case. If the committee agrees with the patient’s position and the medical team remains unpersuaded, the patient’s care should be transferred to another provider within the institution. If the institutional review supports the medical team’s position, and the patient or her proxy cannot be persuaded, the patient should be transferred to another facility. If no other facility will agree to care for the patient, then the specific care can be either prohibited or discontinued.

Medical futility policies are intended to protect the autonomy of all the parties involved. In allowing patients or their surrogates recourse to an institutional review board the criteria laid out by the American Medical Association properly gives both the patient or her surrogate and the medical team a chance to exercise their autonomy. In granting the patient recourse to a review board, the health care center affords the patient the opportunity to appeal a physician’s decision concerning appropriate care to verify that his objective judgment about the suitability of a particular procedure is truly unethical. Should the board of ethics determine the procedure is unethical, the patient can still then exercise their autonomy by seeking out another health care center. If no other center would be willing to take the patient, then the patient should be confident that what they are requesting is truly unethical. Likewise, by allowing a physician to transfer a patient that is requesting what he believes to be immoral care, the policy allows the physician to maintain his integrity without violating the patient’s autonomy.

Medical futility policies are rooted in the concept of medical standard of care. After investigating the cases of Hall v Hiburn, McCourt v Abernathy, and Johnson v St. Francis

Medical Center, Moffett and Moore (2011) defines the medical standard of care as “that which a minimally competent physician in the same field would do under similar circumstances” (p. 111). By appealing to other professionals, futility policies determine if the care being requested is something that other competent physicians would do. Since as Bal (2008) notes, medical malpractice demands proof that the physician was negligent and failing to follow the standard of care, futility policies serve not only as a check that the treatment being rejected was truly in violation of good medical practice, but it also serves as an insurance policy for the physician by providing proof that he was not negligent.

The American Medical Association’s (2008) futility policy is an ethical way of moving past the impasse between Mary’s surrogates and her medical team. By seeking another provider, Mary’s medical team will be free to excuse themselves from participating in the treatment they believe is torture while allowing Tom and John to continue with the care they believe is most ethical. If no other provider is willing to care for Mary with the treatment being requested by Tom and John, then the physicians should have confidence in refusing further life-sustaining treatment without fear of legal or institutional repercussions and Tom and John should have the confidence that the medical community agrees to change Mary’s code status to DNR is the ethical course of treatment.

Conclusion

Tom and John’s insistence that everything medically possible be done for Mary has left the medical team feeling like they are torturing her. The medical team is comfortable continuing to care for Mary by providing the care that she is currently receiving, but they believe that any further care is tantamount to torture and want Mary’s code status changed to reflect the decision to provide no further life-sustaining medical care to Mary. Having arrived at a moral impasse about how to proceed with Mary’s care the morale of Mary’s surrogates along with her healthcare team is seriously suffering. Additionally, this inability to come to a consensus about the best possible treatment plan has left Mary’s future care in jeopardy. Rather than remain at the impasse while hoping that nothing worse happens to Mary, recourse is needed for another party to help break the impasse and determine the best possible care for Mary.

Mary’s surrogates and the medical team should heed the call of the AMA and bring this case to an institutional review board. In applying the AMA’s standards for a medical futility policy, the medical team’s autonomy will be respected by allowing them to choose to proceed with treatments that they determine to be torture, while providing Tom and John with a clear indication of whether another physician in the hospital or another healthcare facility will treat Mary according to their requested standards. If no other medical team is willing to provide Mary with full code status, then her status should be changed as requested by the current medical team.

The Catholic Context

Tom and John base their strong desire that everything medically possible be done for Mary on their understanding of the teachings of the Catholic faith. Ultimately, they believe that the Catholic Church requires them to do everything in their power to save Mary. When the medical team explained the potential treatment, options that will result in extreme pain and little benefit, Tom and John acknowledged the pain that will come with future treatments, but they understood the pain as an opportunity for Mary to participate in redemptive suffering.

Like Tom and John, the healthcare team believes their decision to refuse further life-sustaining treatment is consistent with the teachings of the Catholic Church. Understanding further treatment to be torture they rightly recognize the Catholic Church teaches, "that the prohibition against torture cannot be contravened under any circumstances" (Pontifical Council For Peace and Justice, 2005, par 404). The UN General Assembly (1985) defined torture as "any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person … based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity" (1.1.1). Since Tom and John are acting in an official capacity as Mary's guardian and want to inflict severe physical pain on the grounds of faith-based discrimination, the medical team argues that further life-sustaining treatment would be torture. The belief that further life-sustaining treatment is tantamount to torture in addition to the hospital's Catholic identity and mission should prohibit them from providing that care because it would violate Mary's dignity.

Ultimately both Mary's surrogates and the healthcare team are making an appeal to the teachings of the Catholic Church for their reasons to insist on or refuse treatment. When closely evaluated it becomes clear that Tom and John’s insistence on extraordinary care for Mary is rooted in a misunderstanding of Church teachings in regards to end of life care and redemptive suffering.

Proportionate and Disproportionate Care

Catholics believe that God made the human person to reflect His goodness and to share in the eternal life of heaven (Kelley, 1969). In order for someone to reflect God’s goodness and attain sainthood, they must first have a right to life. The right to human life, then, is a fundamental good that should be preserved because it is necessary for any other good, including the good of sainthood, to be achieved.

The purpose of mortal life is not to live on earth for eternity. The good of human life is rooted in the dignity of the person as a child of God, created and destined to live for eternity in heaven. While human life is good, it is not an end in and of itself and does not need to be preserved at all costs. Rather, the good of human life may be sacrificed for another more perfect good.

When determining whether one has the obligation to seek to preserve their life, the Church teaches that “one is held to use only ordinary means - according to circumstances of persons, places, times and culture - that is to say, means that do not involve any grave burden for oneself or another” (Pius XII, 1957, p.311). Pope Pius XII (1957) continued, “on the other hand, one is not forbidden to take more than the strictly necessary steps to preserve life and health, as long as he does not fail in some more serious duty” (p.311). In determining if a person has the obligation to preserve their life, they must weigh the balance between the preservation of life with other goods.

When weighing these goods, the wellbeing of the whole person must be taken into account. “Therapeutic procedures that are likely to cause harm or undesirable side-effects can be justified only by a proportionate benefit to the patient” (US Conference of Catholic Bishops, 2009, Directive no 33). A treatment should be considered disproportionate if it does not “provide a reasonable hope of benefit without imposing excessive risks and burdens on the patient or excessive expense to family or community” (US Conference of Catholic Bishops, 2009, Directive no 32). When weighing whether a treatment is proportionate or not, the Sacred Congregation for the Doctrine of the Faith (1980) taught that the risks, including the complexity and cost (including physical, mental, emotional, spiritual and societal) of the procedure, must be weighed with probabilities of success, especially in light of the physical and moral condition of the patient.

The medical team has expressed the concern that in their professional opinion any further life-sustaining treatment may be successful in prolonging Mary’s earthly life, but it will come at the cost of extreme pain for Mary and will not provide her with the opportunity to regain her health. Since any further life-sustaining treatment will ultimately fail to facilitate a cure for Mary and it will come at a great burden it constitutes disproportionate care and therefore is not obligatory.

Redemptive Suffering

Tom and John attempt to justify Mary’s pain through the Catholic teaching of redemptive suffering. The Catholic Church (1994) teaches that “by his passion and death on the cross Christ has given a new meaning to suffering: it can henceforth configure us to him and unite us with his redemptive Passion” (par. 1505). This teaching on redemptive suffering is rooted in the recognition that each baptized person is a part of the Body of Christ. (1 Cor 12:27) Through accepting and offering one’s suffering, the person can either then offer it for the physical or spiritual needs of another.

Redemptive suffering is a free choice to accept and offer one’s suffering for the good of herself or another. Since Mary only has the mental capacity of a three-year-old, she does not have the mental capacity to freely choose to accept her suffering and offer it up for her good or for the good of another. Without the ability to accept the suffering, Tom and John’s appeal to redemptive suffering as a means of addressing the extreme pain and suffering that will be inflicted upon Mary in providing further life-sustaining treatment does not serve to justify the torture that they are requesting the healthcare team inflict upon Mary.

Conclusion

Catholic hospitals are called to continue the healing mission of Christ. Their mission calls them to offer treatment to patients who will benefit from it. At the same time, the US Conference of Catholic Bishops (2009) reminds Catholic hospitals that “Jesus’ healing mission went further than caring only for physical affliction. He touched people at the deepest level of their existence; he sought their physical, mental, and spiritual healing” (p. 6). The hospital should seek to restore health when possible, but when that is not possible they should seek to provide comfort for those under their care.

Mary’s healthcare team has come to the conclusion that any further life-sustaining treatment would be inappropriate because while it could keep Mary’s physical body alive, it would be tantamount to torture and there is never a justification for torture. Tom and John understand the pain Mary will experience due to the treatment, but believe the Catholic Church demands that they keep her alive by all means possible and thereby justify the cost of suffering by claiming that she can offer it up for spiritual good. A close evaluation of the Catholic

Church’s teaching on proportionate and disproportionate care shows that any further life-sustaining treatment is disproportionate care, which is not required. When the Church’s teaching on redemptive suffering is fully understood, it is clear that Mary does not have the requisite mental capacity to choose to participate in the suffering of Christ and thus Tom and John’s expressed desire for Mary to balance the suffering with redemption does not exist. The true understanding of Mary’s condition and the teachings of the Catholic Church demonstrates that providing further life-sustaining treatment is in fact torture, which is prohibited by the Catholic Church.

Conclusion

The history of healthcare is closely connected to the Catholic Church. For 2,000 years, followers of Christ have heeded His command to heal the sick (Lk 9:2) recognising that whatever they do to the "these least brothers of mine, you did for me." (Mt 25:40) Today Catholic hospitals seek to continue that healing ministry of Jesus Christ.

As medicine advances, many new treatments are becoming available, which would have been unimaginable even 10 years ago. While these treatment options have the power to do a great amount of good, when these treatments are used inappropriately they can violate the dignity of the patient. These recent advances have left Catholic hospitals facing many challenges in discerning if a particular treatment is truly treatment or if it is torture.

Recently, a Catholic hospital faced this ethical dilemma when Mary, a fifty-year-old with the mental capacity of a two-year-old was admitted for a post-surgical infection. Mary's case demonstrates the tension that healthcare teams in Catholic institutions often face when trying to treat their patients with dignity. Mary's surrogates, Tom and John, demanded that every medical treatment option was offered to keep Mary alive, but the medical team believed offering any additional life-sustaining treatments would only serve to torture Mary rather than treat her. When faced with these types of moral impasses, both the patient, or her surrogate, and the healthcare team need tools and policies to help them break the impasse to continue treating the patient as they would treat Christ.

The process of discerning if a medical procedure is a treatment or torture requires the clinician to sort through many different factors. Only after all of the facts have been organized and analyzed can the patient, her surrogates, and the medical team have an intelligent conversation about the ethical way forward. Marugg, Atkinson, and Fernandes' (2014) five-box method is an effective tool for organizing the many facets of a particular case, while also highlighting the moral principles that are relevant to the case.

The five-box method is an adaption of Johnson, Siegler and Winslade’s (1998) four box method which proposes that every clinical case can be evaluated by means of the four key topics of medical indications, patient preferences, quality of life, and contextual features. The first box, medical indications, evaluates what medical treatments options are available to focus on the diagnosis and treatment of the patient’s medical condition. The patient preference box discerns the patient, or her surrogate, desires about how she wishes to be treated. The third box evaluates how the treatment will affect the quality of life for the patient and the fourth box, evaluates the specific case in light of the larger community. Marugg, Atkinson, and Fernande (2014) added the fifth box, which integrates the principles of Catholic social and ethical teaching.

When Mary’s case is investigated within the context of the five-box method, a path through the moral impasse begins to emerge. The medical indications show that Mary’s treatment has left her body very worn down and there is no medical indication that she will be able to recover to a point where she could be discharged from the intensive care unit. While Mary’s surrogates, Tom and John, have made it clear that they want Mary to be discharged to live with Tom, a thorough evaluation of the patient’s preference indicates that going against Tom and John’s stated desires may actually be the ethical recourse. When Mary’s quality of life is evaluated, it begins to become clear that Tom and John’s desires for Mary’s medical care will only serve to violate her dignity. Ultimately an evaluation of the contextual features shows that a proper decision about whether to offer Mary further life-sustaining treatment or not demands recourse to a due process.

Unable to come to an agreement, the hospital is left with no other choice than to make use of the futility policy lay out by the American Medical Association (2008). If the review board supports the medical team’s assessment that further treatment is inappropriate and no other healthcare institution will agree to care for Mary, then everyone should feel confident that Mary’s due process has been respected and the truly ethical course of action is to continue her treatment, but not to provide any further life-sustaining treatment. Ultimately, while Tom and John may not agree with the decision, an evaluation of the Catholic identity box makes it clear that this position is in line with their Catholic faith.

As Mary’s family and medical team look out for her best interests they find themselves at a moral impasse. Since nether Tom and John nor the medical team can see a path through the impasse, the hospital should insist on having the case heard at their institutional review board. When the five-box method is employed to look objectively at Mary’s care, it becomes clear that any further life-sustaining treatment would only serve to violate Mary’s dignity. While hard to accept, the hospital should continue to provide Mary with the care she is receiving, but as respectfully as possible inform Tom and John that the hospital will not agree to provide any further life-sustaining treatment. The hospital should further agree to cooperate in transferring Mary to another qualified facility if they will agree to care for her.

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Appendices

Literature Review

The study of bioethics is a multidisciplinary and interdisciplinary study which incorporates a wide array of academic disciplines. It is a melting pot where ideas from many different disciplines come together to assess human actions in accordance with the human person's relationship to the natural world. This literature review seeks to provide a summary of content contained in the previously submitted annotated bibliographies covering the disciplines of faith and reason, law and bioethics, healthcare and biomedical industry ethics, medicine and bioethics, and health policy.

faith and reason

The Catholic Church has always upheld the sanctity and the dignity of every human life. Both the hospital, which is a Catholic institution and Mary's surrogates, who are Catholic, are seeking to respect Mary's dignity. Understanding the Church's teaching on human dignity and its application end of life care is essential if Mary's surrogates and the medical team are going to come to a consensus about Mary's care.

The Sacred Congregation for the Doctrine of the Faith (1980) places the dignity of the human person in the context of end of life medical decisions. This official Church document is divided into four sections: the value of human life, euthanasia, the meaning of suffering and the due proportion in the use of remedies. It upholds the Church's teaching that while proportionate care must always be pursued disproportionate care may be foregone.

Pope John Paul II (1995), cited the *Declaration on Euthanasia* to reiterate the intrinsic evil of euthanasia. Like the Sacred Congregation for the Doctrine of the Faith, the Holy Father took the opportunity to express the truth of redemptive suffering while furthering the discussion on the true meaning of freedom and autonomy. Ultimately the pope reiterates the teaching that while it is permissible to refuse disproportionate treatment that would only result in prolonging life with a great burden, proportionate care must always be continued.

The Church's teaching while based on faith is also rooted in natural reason. Austriaco (2011) situates the eternal truths about the dignity of the human person in the light of virtue. He situates the questions surrounding end of life care including the meaning of death, the refusal of medical care at the end of life, do not resuscitate orders, euthanasia, etc. in a context that applies to both Catholic and secular institutions.

law and bioethics

For better or for worse, the law is an integral part of bioethical decision making. Often fearing a lawsuit, medical teams can be tempted to treat according to what is legal instead of what they know to be ethical. In cases like Mary's where emotions are high and death may be near, it is important for the legal issues to be resolved with the ethical issues. For this case, in particular, the issues of surrogacy and futility policies must be analyzed.

The landmark case for medical futility is *In re Baby "K"* where the court held that if a physician refuses to treat a patient, they cannot completely abandon them. This ruling effectively places the physicians right to refuse care that violates their personal or professional ethical standards below a patient's desire to live. Yet *in re Baby "K"* does not set a legal precedent requiring physicians to always follow their patient's desire to live. Luce and Alpers, (2000) propose that it may be legally acceptable for physicians to refuse life-sustaining treatment in some cases by appealing to the legal understanding of malpractice. They argue that since malpractice is acting against the appropriate standard of care in a manner that harms the patient if the continuing of life-sustaining treatment violates the standard of care, the physician could refuse the care without concern of legal repercussions. Paris, Cassem, Dec, and Reardon (1999) show that the decision to refuse life-sustaining treatment was upheld by a jury in the case of *Gilgunn v MGH* where the jury ultimately held that the hospital's decision with withholding CPR did not equate to any liability.

medicine and bioethics

So often when people think of medicine they only think of physical healing. Yet there is so much more to good health care than simple physical healing. In Mary’s case, Tom and John’s sole focus on physical healing comes at the cost of the overall integrity of Mary. Gross and Hilliard (2009) show the importance of addressing not only the physical condition of the patient but also providing them for their spiritual, emotional, psychological and moral suffering. In introducing the discipline of palliative care they stress the importance of spiritual care, pain management, and the meaning of suffering for people in Mary’s condition.

The advances of modern medicine have left many people with a false sense of hope, that every medical condition can be cured. While no one wants to think about the possibility of death, even with the advances in medicine, death is a reality that must be considered. Nelson’s (2012) interview shows the benefits of palliative care in the intensive care unit. By involving palliative care, essential dialogue can be established and continued which will help the family and medical team agree on the best approach to the end of life care. Tang (2010) stresses the importance of dialogue especially when DNR orders are given. He argues that even when a DNR is ordered dialogue must continue to ensure that an acceptable level of care is properly addressed with the patient or surrogate.

health policy

Patients and healthcare providers can easily become divided over the issue of torture or treatment. When patients and healthcare providers find themselves in a similar situation to

Mary’s case, the Center for Practical Bioethics (2016) promotes a 6-step medical futility policy which is firmly rooted in the core secular principles of bioethics. This policy gives a helpful path forward when the medical team and patient cannot agree on whether a particular form of care is futile or not. While many academics and professional organizations have composed futility policies, Texas was the first state to legislate a futility policy. Kapottos and Younger (2015) analyze Texas’ policy. They show that in allowing a healthcare facility to stop life-sustaining treatment after giving 10 days notice, they allow the bias of the ethics committee to shine through and deny people recourse to due process. Moore (2007) takes a more positive view of the Texas Advance Directives Act. He argues that it strikes a needed balance between patient autonomy and the standard of care. After analyzing three possible avenues of approach for when patients and medical teams disagree about futile treatment (the refusal of treatment by the patient, doing whatever the patient wants, bringing the case for judicial review) and demonstrating their weaknesses he argues the only possible reasonable approach is a futility policy.

healthcare and biomedical industry bioethics

Healthcare and biomedical industry bioethics is the point of convergence for faith and reason, law and bioethics, medicine and bioethics, and health policy. This field of bioethics challenges hospitals to integrate their values in a manner that enables all members to practice in a manner consistent with those values. Henson (2012) addresses the importance of palliative care for the mission of a Catholic hospital. He shows how palliative care is a true expression of Catholic healthcare for those facing life-threatening conditions.

The integrity of the hospital's mission and values must be protected by every member of the hospital. When a member of the hospital believes a course of treatment violates the mission and values of the hospital they must have recourse to protect the hospital's integrity. Yet a proper implementation of these visions and values recognizes that individual members of the hospital cannot implement them as they please. Rather when disagreements arise the Council on Ethical and Judicial Affairs (1999) recommends a 6 step process. Integral to this process is the proper implementation of an ethics committee. O'Brien (2009) defines the role of an ethics committee while discussing their composition and structure. He then argues that a good ethics committee is invaluable for establishing the Catholic identity of a hospital.

4 Box Method

The Four Box Method as adapted from: Johnson, A. R., Siegler, M., & Winslade, W. J. (1998). *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine, Fourth Edition*. New York, NY: McGraw-Hill Education / Medical

Medical Indications

1. The patient's medical condition.
2. Possible medical treatment exist.
3. The purposes and goals of treatment.
4. Benefits and harms of the treatment.

Patient Preference

1. The patient's competency to make decisions
2. If the patient is not competent who is the appropriate surrogate?
3. Does the patient or her surrogate have all the information she needs to make a decisons?

Quality of Life

1. The patient's understanding of quality of life.
2. How will the treatment or lack of treatment affect the patient's quality of life?

Contextual Features

1. Are there legal issues that could impact the case?
2. Are there financial factors?
3. Are there public health factors?

The Fifth Box

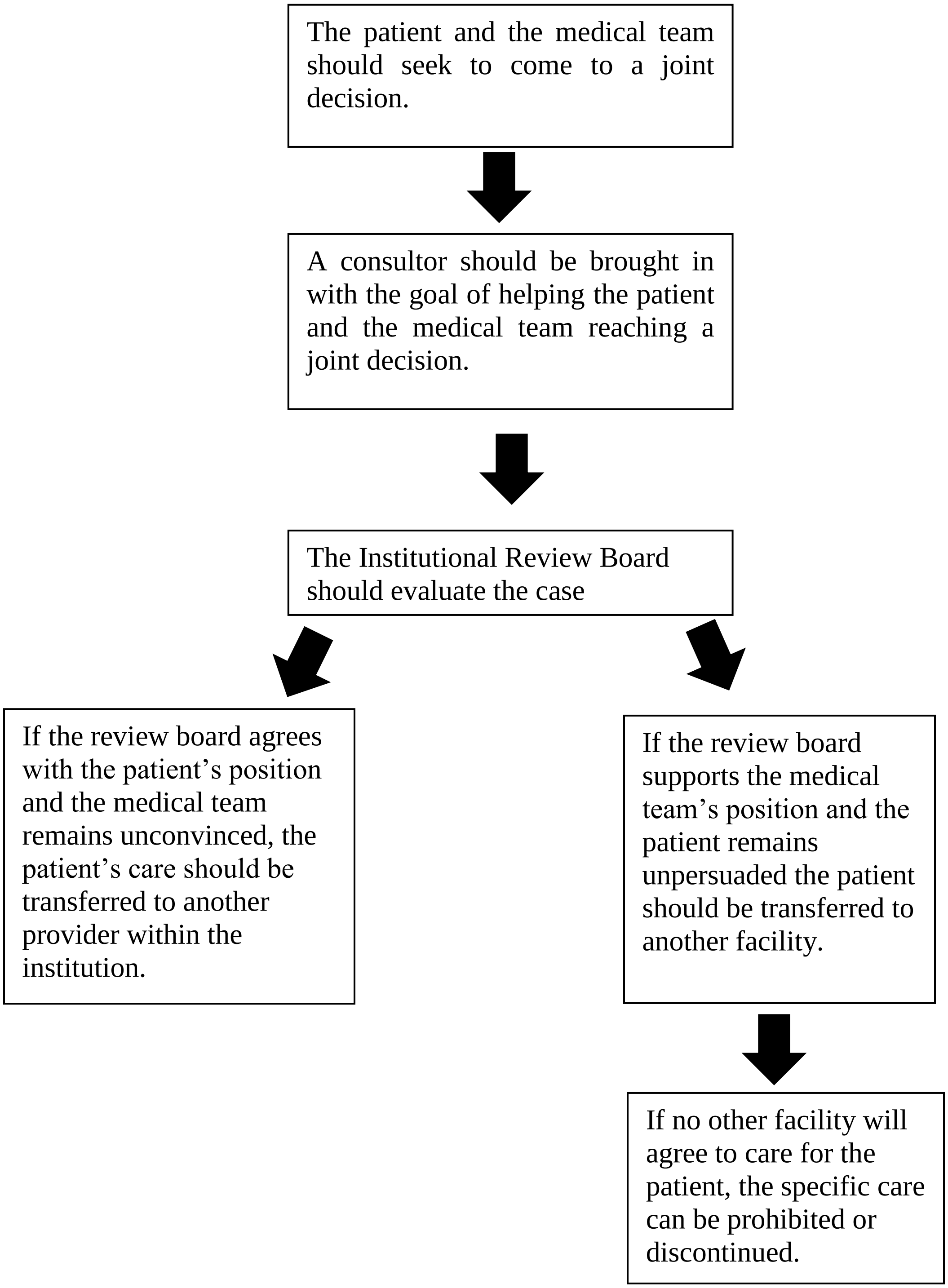
The Fifth Box as adapted from Marugg, L., Atkinson, M., and Fernandes, A. (2014). The Five-Box Method: The "Four-Box Method" for the Catholic Physician. *The Linacre Quarterly, 81*(4), 363-371. doi:10.1179/2050854914y.0000000032

The Catholic Context

1. Does this treatment respect the dignity of the patient as a child of God?
2. How does Catholic Social Teaching apply?

AMA 2008 Futility Policy

The American Medical Association's Guide to Futility Policies adapted from American Medical Association. (2008) *Code of medical ethics of the American Medical Association: Current opinions with annotations*. Chicago: AMA Press.



The patient and the medical team should seek to come to a joint decision.

A consultor should be brought in with the goal of helping the patient and the medical team reaching a joint decision.

The Institutional Review Board should evaluate the case

If the review board agrees with the patient's position and the medical team remains unconvinced, the patient's care should be transferred to another provider within the institution.

If the review board supports the medical team's position and the patient remains unpersuaded the patient should be transferred to another facility.

If no other facility will agree to care for the patient, the specific care can be prohibited or discontinued.

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St. Paul leaves a clear instruction to the Church in Macedonia, that they should "in all circumstances give thanks, for this is the will of God for you in Christ Jesus" (1 Thessalonians 5:18) As I conclude this paper and the Master of Science Program, it is necessary to heed this command of St. Paul and express my gratitude to so many people who have made this specialized education possible for me. Firstly, I must thank my bishop, Archbishop Robert Carlson, for his support through this program. I must also thank the people of the Archdiocese of St. Louis who so generously support their priests. Secondly, I wish to thank Msgr. Henry Breier and the parishioners of Queen of All Saints Parish who encouraged me in my studies and graciously sacrificed so that I could take the time to complete the Master of Science Program.

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