

Medical Futility: A Paradigm Analysis

Nancy S. Jecker

Theresa Schiavo was twenty-six in 1990 when her heart suddenly stopped beating as a result of a potassium deficiency, possibly caused by an eating disorder. Through the use of cardiopulmonary resuscitation Mrs. Schiavo's heart was re-started, but much of her higher brain function was irreversibly destroyed. The cerebral cortex, which controls all of the qualities that make Mrs. Schiavo a person, such as her memory, emotion, and thought, never returned. She completely lost any awareness of herself and the outside world, and lacks the ability to have conscious experiences of any kind. Yet because Mrs. Schiavo's brain stem is intact, her heart continues to beat; she continues to breathe on her own, often moaning; she can swallow; her eyes are open and can stare or follow objects; she receives nutrition and hydration through a tube inserted into her stomach and has peristalsis and voids into a diaper. Doctors determined that she was in a persistent vegetative state (Goodnough, 2004).

The tragic case of Theresa Schiavo underscores our ambition to forestall death at all costs, regardless of a patient's underlying quality of life. It also shows that work remains to be done in coming to terms with the futility of medical interventions that produce biological effects, but do not produce any benefit the patient ever appreciates. In this paper I use the term "medical futility," to refer to medical interventions where either the *likelihood* of benefit to the patient is exceedingly small, and falls well below a threshold considered minimal, or the *quality* of outcome associated with the intervention is exceedingly poor, and falls well below a threshold considered minimal (Schneiderman, Jecker and Jonsen, 1990). In cases such as Schiavo, the qualitative aspect of futility is paramount. Although the use of artificially administered nutrition and hydration can produce a desired physiological effect, i.e., nourishing the body, it cannot provide any benefit that the patient ever perceives.

At the time this paper is being written, Mrs. Schiavo is being cared for in

a Tampa, Florida nursing home. Her parents, Robert and Mary Schindler, insist that she will improve and does not want to die. The Schindlers, who are Roman Catholic, accept Pope John Paul II's statement that it is wrong in principle to withhold food and water from people in a persistent vegetative state (Goodnough, 2004). Yet Mrs. Schiavo's husband and legal guardian, Michael Schiavo, disagrees. Mr. Schiavo, a nurse, stated that his wife told him and relatives on several occasions that she would not want to have her life artificially prolonged (Goodnough, 2004). In 1998, he went to court to have his wife's feeding tube removed. Although lower courts generally sided with Mr. Schiavo, and the feeding tube was eventually removed, the case quickly became a rallying point for conservative religious groups. In October, 2004, the republican-controlled Florida legislature passed a one-time-only law that reversed a series of lower court rulings and allowed Florida's Governor, Jeb Bush, to order the feeding of Mrs. Schiavo through a tube. Mr. Schiavo appealed to the Florida State Supreme Court, which found the law unconstitutional and a violation of the separation of church and state (Baranauckas, 2004). Currently, Mrs. Schiavo continues to receive artificial nutrition and hydration, and it remains to be seen whether or not the Florida State Supreme Court decision will be appealed to the U.S. Supreme Court and, if it is, whether the decision will be upheld.

This paper asks what the case of Theresa Schiavo teaches us about the current state of the medical futility debate. One answer to this question is that Schiavo shows that no progress has been made since Karen Ann Quinlan (1976), the twenty-one year old woman in a persistent vegetative state whose parents went to court in the 1970s to have a ventilator removed. I will argue that this response is misguided. My argument employs a casuistic approach. Rather than beginning with conceptual ideas, such as medical futility, or moral rules, such as physicians should not use futile therapies, I instead intend to stay close to the cases and circumstances that characterize the debate. My method will be to look carefully at a series of cases involving withholding and withdrawing treatment. On the basis of these cases I identify more general "paradigms," or families of cases that are grouped together because they are related in some ethically significant way(s). On the basis of the resulting paradigms, I will piece together a map of morally significant likenesses and differences. This approach has sometimes been called a "moral taxonomy" (Jonsen and Toulmin, 1988, p. 14). A moral taxonomy enables us to place new cases, such as Schiavo, on a map with familiar territory. We can then see more readily which cases the new case is like, and what has been said about such cases in the past. Ultimately, my aim is to show that our reasoning about various sorts of futility cases redundantly yields certain types of responses. If this is correct,

we are beginning to reach what Jonsen and Toulmin call “a locus of certitude,” or “a shared perception of what [is] specifically at stake in particular kinds of human situations” (1988, p. 18).

Introduction to the Cases

One of the earliest sorts of futility cases dealt with withholding and withdrawing CPR in the hospital setting from patients for whom CPR is rarely effective due to an underlying disease condition. The case Blackhall describes, summarized below, is illustrative.

Case One: Futile use of CPR in the hospital setting on an adult patient with failed chemotherapy for myelogenous leukemia and pneumonia not responding to antibiotics.

A 30-year-old woman with acute myelogenous leukemia who had relapsed from her second remission approximately one month earlier was started on an experimental chemotherapeutic regimen that left her with profound neutropenia and thrombocytopenia for almost four weeks. After four weeks, a bone marrow biopsy revealed regeneration with blasts, indicating failure of chemotherapy. The patient also had pneumonia thought to be fungal, which was not responding to treatment with broad-spectrum antibiotics....She (with her family) was asked, “if your heart or lungs stop working, do you want us to pump on your chest and put you on a breathing machine?” The patient and her family decided that she should receive a full CPR effort. The house staff and nursing staff were opposed to this decision, and much conflict ensued (Blackhall, 1987, p. 1282).

In this kind of case what was at stake was the low likelihood of CPR benefiting the patient. A series of empirical studies, published in the 1980s and 1990s, showed low survival rates following cardiopulmonary resuscitation (CPR) for various populations of patients. For example, in 1983, Bedell and colleagues reported that the chance of survival following CPR was extremely small for patients with diseases such as pneumonia and renal failure (Bedell, Delbanco, Cook et al., 1983). In a subsequent study of 294 patients at Beth Israel Hospital in Boston, Bedell et al. found that no hospitalized patient with metastatic cancer, acute stroke, sepsis, or pneumonia survived to hospital discharge after CPR (Bedell, Pelle, Maher et al., 1986). These and other empirical studies (Lantos, Miles, Silverstein et al., 1988; Murphy, Murray, Robinson et al., 1989; Blackhall, Ziogas and Azen, 1992; Taffet, Teasdale and Luchi, 1988) contributed to an emerging

consensus that cardiopulmonary resuscitation was not appropriate for every patient. Thus, the standard practice of attempting CPR on every patient who experiences cardiac arrest regardless of underlying illness was no longer valid.

A different group of cases involved situations such as the continued use of a respirator on an adult patient in a persistent vegetative state whose wishes were not directly known. The landmark cases of Karen Ann Quinlan and Helga Wanglie described below are illustrative.

Case Two: Futile use of respirator on an adult in a persistent vegetative state whose wishes are not known

Helga Wanglie was an eighty-five-year old woman who was taken from a nursing home to Hennepin County Medical Center when she developed respiratory failure. She was placed on a respirator, and over a period of several months repeated attempts to wean her from the respirator failed. Mrs. Wanglie was discharged to a chronic care hospital that specializes in respirator-dependent patients. At the time of her discharge she was fully conscious, aware of her surroundings and able to communicate. At the new facility, efforts continued to attempt to wean Mrs. Wanglie from the respirator. During one such attempt, her heart stopped, and she was resuscitated and taken to another hospital for intensive care. She remained unconscious, and was later determined to be in a persistent vegetative state. When physicians suggested that life-sustaining treatment be withdrawn since it was not benefiting Mrs. Wanglie, the patient's husband, daughter, and son insisted on continued treatment (Cranford, 1991).

Case Three: Futile use of a respirator on an adult in a persistent vegetative state whose wishes are not known

Karen Ann Quinlan suffered respiratory arrest apparently following consumption of an overdose of alcohol together with a tranquilizing drug. She would never regain consciousness, but emergency medical intervention stabilized her breathing on a ventilator, leaving her in a persistent vegetative state. Her father, acting on behalf of himself and his wife, sought to be appointed her guardian for the announced purpose of withdrawing the ventilator, even though they believed this action would mean their daughter's death (In the matter of Karen Quinlan, 1976, p. 143).

In the case of Karen Ann Quinlan, the consensus of the treating physicians, as well as several qualified experts who testified in the case, was that removal of the respirator would not conform to medical practices, standards, and traditions. The Supreme Court for the state of New Jersey decided in favor of the family by granting Karen's father the authority to select his daughter's physician.

By contrast, in the 1991 case of Helga Wanglie, the treating physician advised against continued use of a respirator on the ground that it was not benefiting Mrs. Wanglie. The position of the treating physician was consistent with a growing consensus among health professionals. During the decades of the 1980s and 1990s, professional medical associations and bioethics groups began taking positions about the ethical implications of medical futility, and recommending that futile treatments be withdrawn, or be withheld if already underway. Perhaps the earliest statement came from the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. In its 1983 report, *Deciding to Forego Life-Sustaining Medical Treatment*, the Commission cautions that

The care available from health care professionals is generally limited to what is consistent with role-related professional standards and conscientiously held personal beliefs. A health care professional has an obligation to allow a patient to choose from among medically acceptable treatment options...or to reject all options. No one however, has an obligation to provide interventions that would, in his or her judgment, be counter therapeutic (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983, p. 44).

Subsequent statements by the American Thoracic Society (American Thoracic Society Bioethics Task Force, 1986), the American Medical Association (Council on Ethical and Judicial Affairs, American Medical Association, 1991), the Hastings Center (1987), the Society of Critical Care Medicine (Task Force on Ethics of the Society of Critical Care Medicine, 1990), and the American Academy of Pediatrics (1994) explicitly recognized the term "futility," and cautioned physicians against applying futile interventions. The underlying idea seemed to be that medicine, nursing, and other healing professions are not practiced merely on demand, but instead aspire to moral goals, such as helping the sick.

In the case of Helga Wanglie, the family wished to continue aggressive life support measures over the objections of the medical team and hospital. Mr. Wanglie believed that life should be maintained as long as possible, no matter what the circumstances, and asserted that his wife, Helga Wanglie, shared this belief. The judge ultimately decided in favor of allowing the

patient's husband, Mr. Wanglie, to make decisions on Helga Wanglie's behalf. Commenting on the Wanglie case, Miles pointed out that the judge's decision was at odds not only with professional ethics, but also with a growing body of empirical evidence. Calling attention to the fact that we do not have any direct knowledge of Helga Wanglie's preferences because she did not leave any record of her wishes, Miles argued that "A large majority of elderly people prefer not to receive prolonged respirator support for irreversible unconsciousness"; he added, "Studies show that an older person's designated family proxy [often] overestimates that person's preference for life-sustaining treatment in a hypothetical coma" (Miles, 1991, p. 513). Others argued that Mrs. Wanglie's alleged desire for continuous biological existence cannot compel the medical profession or Mrs. Wanglie's physicians to offer care that is professionally recognized to carry no therapeutic benefit, nor can it compel health insurance companies to pay for medically unnecessary interventions created exclusively by a consumer's demand (Rie, 1991).

In contrast to Case One, where the emphasis was on the low likelihood of a patient's surviving CPR, in the cases of Quinlan and Wanglie the primary concern was clearly not whether the respirator would produce a desired physiologic effect, but instead the quality of outcome associated with the intervention. One response to cases such as Quinlan and Wanglie was the use of DNR orders to encourage discussion with competent patients and surrogates about the advisability of future resuscitation efforts (Lo, Saika, Strull et al., 1985). Yet this approach was limited. As Brett and McCullough argued, in the absence of at least a "modicum of medical benefit" (Brett and McCullough, 1986) CPR should not be presented and discussed as a medically viable option. Presenting it as such can mislead both patient and family, by suggesting that the patient can survive or improve, despite evidence that the treatment was almost certain to fail. It also can yield intractable situations, in which patients and families want "everything possible to be done," rather than asking for interventions that will help the patient. Thus, in Case One above it could be argued that the option of CPR should not have been offered to the woman with myelogenous leukemia and fungal pneumonia.

In the same family of cases as Quinlan and Wanglie is the case of Baby K, an infant born with anencephaly. The cranial vault of infants born with this condition is completely absent, and their cerebral hemisphere either completely missing or reduced to small masses attached to the base of the skull. Most anencephalic infants are stillborn or die within hours or days of birth. Like Quinlan and Wanglie, liveborn anencephalic infants with lower brain functioning do not meet the whole brain definition of death:

irreversible cessation of all functions of the entire brain, including the brain stem, has not occurred. In the case of Baby K, debate centered on repeated use of emergency CPR in response to respiratory distress.

Case Four: Futile resuscitation of an anencephalic infant

Baby K was born missing most of her brain and doctors caring for the baby say she will never think, hear, or see. Now 16 months old, Baby K is placed on a mechanical ventilator whenever she has trouble breathing, following the patient's mother's wishes for medical treatment. Although Baby K lives at a nursing home, Baby K has been taken to a hospital in Fairfax, Virginia at least three times with severe respiratory problems. The child's mother has stated that she wants God to decide when her child will die. Baby K's doctors have argued that mechanical ventilation will do nothing to ameliorate the child's brain damage and underlying condition, and the hospital where she is being treated has requested court permission to deny emergency treatment ("Hospital care ordered for girl missing most of brain," 1994).

Similar to Wanglie, Baby K's family requested life-saving treatments against the wishes of the treating physician and hospital. The American Academy of Pediatrics brief filed with the Court supported the hospital and physicians in the Baby K case on the ground that life-sustaining treatment for an anencephalic baby was medically inappropriate (Greenhouse, 1993). Dissenting opinion, expressed for example by Veatch, who testified for the mother at the trial, was that the decision to continue treatment "is well within the range of parental discretion....When the mother demands to go on, I don't see any basis for disagreeing with her" (quoted in Greenhouse, 1993). Yet, against this position, the hospital argued that the appropriate treatment for anencephaly is limited to nutrition, hydration, and warmth, and that mechanical ventilation fell outside the prevailing standard of care (Flannery, 1995).

In Baby K, like Quinlan and Wanglie, the court ultimately decided in favor of the family, and held that the Emergency Medical Treatment and Active Labor Act (EMTALA) requires ventilatory assistance be provided to Baby K. The court also held that Baby K's mother has a constitutionally protected right to make decisions about Baby K's care, seemingly without limits. Commenting on this case, Clayton argues that it is appropriate to decline to provide medical interventions to individuals who will never (re)gain consciousness, because they will never perceive any benefit from these treatments (Clayton, 1995). Baby K will never think, see, hear, feel

pain, or interact with her environment in any way.

A somewhat different set of cases involves patients or families who request futile interventions for a patient who meets criteria for brain death. In contrast to the cases discussed so far, in the following case there is irreversible cessation of the entire brain, including the brain stem.

Case Five: Futile use of a respirator on a brain dead teenager

Teresa Hamilton was a thirteen-year old with diabetic ketoacidosis who was admitted to the hospital and shortly after fell into a coma. Physicians caring for Teresa determined that she was legally dead after three brain scans showed no brain activity and a blood scan indicated no blood flow to the brain. But the patient's parents, Frederick and Sharon Hamilton, asked the hospital to do everything to keep their daughter alive. The hospital went to court asking for direction because the parents' wishes conflicted with hospital policy ("Hospital fights parents' wish to keep life support for a 'brain dead' child," 1994, p. 6).

With respect to the Teresa Hamilton case, Annas has argued that "The hospital has an obligation to take her off the ventilator....Now they are treating a corpse....You really do confuse the parents, because you lead the parents to believe that the child is still alive" ("Hospital fights parents' wish to keep life support for a 'brain dead' child," 1994, p. 6). Commenting on a similar case, in which the family of a brain dead man refused to consider terminating ventilator support, Freer emphasizes the importance of beginning with an educational and supportive approach, with the fallback position for a completely uncooperative family being discontinuing the ventilator against their wishes (1992). Similarly, Clayton emphasizes that "while clinicians, like other people, must approach all patients with care and respect, the time has come to recognize that it is wrong to ask health professionals to provide ventilatory assistance to Theresa Hamilton, Baby K, and other permanently unconscious and brain dead patients, and certainly wrong to insist that clinicians do so against their wishes" (Clayton, 1995, p. 14).

A different sort of futility scenario involves patients with an extremely poor prognosis and quality of life, yet who retain consciousness and higher brain function, and thus are not brain dead or in a persistent vegetative state. Like Case One, the case described below focuses on the poor likelihood of survival. Yet it warrants separate treatment because the outcome of this case defied the odds. Despite the overwhelming likelihood of death, the patient survived. For this reason, the case is sometimes pointed to as vindication of

the view that futile treatments should be used whenever families or patients request them, regardless of the low probability that they will produce a desired physiologic effect.

Case Six: Life-sustaining treatment for an infant with kidney failure, bowel obstruction, and brain damage who “beats the odds”

Ryan Nguyen was born six weeks prematurely with a weak heartbeat and poor blood flow to his organs. His physicians at Sacred Heart Medical Center in Spokane, Washington, employed heroic measures to revive him. A few weeks after his birth, it became clear to Ryan’s doctors that the aggressive medical interventions keeping him alive were futile and should be withdrawn. Ryan had multiple medical problems including kidney failure, bowel obstruction, and brain damage. To survive, Ryan would require kidney dialysis for approximately two years, followed by a kidney transplant, a feat most consulting experts on kidney disease agreed was ‘virtually impossible to pull off’. However, a physician in Portland, Oregon, who read news accounts of the case agreed to admit Ryan to Legacy Emanuel Children’s Hospital. Once there, Ryan’s condition improved; he was taken off the ventilator and began to breath independently. He underwent surgery to correct a bowel obstruction. When doctors removed him from dialysis, he was able to urinate on his own. After hospital discharge, Ryan’s kidneys were functioning at about three-fourths of normal capacity and would eventually wear themselves out. Thus Ryan would eventually require a kidney transplant (Jecker, 1995).

On the basis of cases such as Baby Ryan, it can be argued that no one can foretell the future; there is in every case a “chance,” however slim, of beating the odds. Just as Baby Ryan’s condition improved, there was a chance that Helga Wanglie would wake up from her coma and a possibility that a miracle would happen and Theresa Hamilton, who was brain dead, would come back to life. I return to these points in the analysis below.

Mapping the Moral Domain

Listing cases in an ordered fashion helps us to see more clearly their salient ethical features. All of the cases described here share common features. Thus, in all of the cases the interventions in question provide an exceedingly poor likelihood or quality of benefit for the patient. This is why they are all cases that fall under the heading of futility. Within futility, there is a further

division, noted earlier, between quantitative and qualitative futility. In cases such as one and six involving quantitative futility, there is an overwhelming *likelihood* that an intervention will fail to produce a desired effect. For example, the evidence suggests that the patient in Case One with metastatic cancer and pneumonia will not survive to hospital discharge regardless of whether CPR is used. In cases such as two through four, involving qualitative futility, a desired physiologic *effect* can be achieved, but it does not offer a significant *benefit* to the patient. Thus in cases such as two and three, patients in a persistent vegetative state cannot experience any benefit from air forced in and out of their lungs by a respirator. The permanent absence of consciousness implies that regardless of the physiologic effects that can be achieved, there is no comfort or help medicine can provide to the patient. In the most extreme scenario (Case Five), the patient is dead and “life support” fails to support life in any form.

Qualitative Futility

In addition to the general division between quantitative and qualitative futility, there are further useful distinctions, based on the circumstances of the patient. Within the domain of qualitative futility, we can distinguish (1) patients who are brain dead, (2) patients who permanently lack higher brain function, and (3) conscious patients who experience overwhelming suffering for a predictably brief period of time, or are totally dependent on intensive medical care. We respond differently to cases falling under these groups. For example, someone who is entirely comfortable withdrawing a respirator from a dead patient may respond differently to an anencephalic infant or a patient in a persistent vegetative state. Is there any ethical backing for treating patients in groups (1), (2) and (3) differently?

Let us start with the middle category: (2) patients who permanently lack higher brain function. It can be argued that neither individuals in a persistent vegetative state nor infants born with anencephaly are “persons,” in the moral sense, because personhood is typically associated with certain intrinsic qualities, such as conscious awareness of one’s self or one’s surroundings, the ability to experience pain and pleasure, or the capacity to interact with others. Even some of the most conservative positions about personhood require at least the *potential* for attributes such as these. Thus, conservatives on the abortion debate argue that at the moment of conception the fertilized egg has the *potential* to develop these morally important qualities. By contrast, the anencephalic infant and the individual in a persistent vegetative state wholly lack this potential.

Yet what makes Karen Ann Quinlan and Helga Wanglie different from a

fetus is that they are *past persons*. By contrast, no one argues that the fetus was a person prior to conception. Moreover, we do not typically treat patients in a persistent vegetative state as non-persons. This may reflect the fact that although patients such as Karen Ann Quinlan and Helga Wanglie do not meet the usual criteria for being moral “persons” and are not persons in a strict philosophical sense, they nonetheless are regarded as persons in a social sense. That is, they continue to be granted moral standing by us, perhaps by virtue of their historical personhood. Although there is arguably no moral person who survives when only brain stem activity remains, there is still a past person, someone with a life story, and possibly with clearly expressed past wishes and values that merit respect.

In contrast to Quinlan and Wanglie, Baby K is not a past moral person. What moral standing could Baby K possibly have? Arguably, if Baby K has any moral standing it derives from the fact that this infant is important to persons, namely the mother who gestated and bore Baby K, and the doctors and nurses who delivered and care for Baby K (Jecker, 1990). Although an infant born with anencephaly lacks intrinsic qualities such as consciousness, it possesses the relational qualities of being someone’s patient, someone’s daughter or son, someone’s sister or brother. However any relationship with an infant in this condition is inherently limited. It will inevitably be short-lived and non-reciprocal. One could question whether it is properly called a “relationship” at all, since one party has no possibility of ever being aware of the other. If relationships are interpersonal, they presumably exist between people. Thus, it could be argued that there is no present relationship possible with a person in a persistent vegetative state or with an infant born without a higher brain. If this is correct, than Helga Wanglie and Karen Ann Quinlan have moral standing solely on the basis of their history of personhood and personal relationships, whereas Baby K has no moral standing on these bases.

Yet what degree of moral importance do we assign to personal relationships that no longer exist? Personal relationships we have had with someone who is now in a persistent vegetative state take on a historical quality, just as personal relationships we have had with someone who is now dead. Thus, I continue to have thoughts and feelings about my dead mother, yet these thoughts and feelings exist only inside me. Similarly, in the case of a person in a persistent vegetative state, there are thoughts and feelings about the person who used to be. Yet there is no longer an interaction between persons. While we see and respond to an individual in a persistent vegetative state, they do not see or respond to us. In this sense, what exists in the encounter is a unilateral response, not an ongoing interpersonal relationship. When I visit my mother’s gravesite, the encounter I have with her remains is

one-sided because I can only imagine her response. What is different about Baby K is that unlike my deceased mother, Baby K has no history of personal relationships with others.

Let us explore further the case of the infant with anencephaly, and compare it with the case of the brain dead patient. Presumably, the fact that Baby K is alive makes her situation morally different from the situation of a patient, such as Theresa Hamilton, who is dead. Why are they morally different? What would the argument in support of such a claim look like? We often hear people say that “life has intrinsic value.” But such a claim is terribly vague. After all, we routinely slaughter and consume animals, which are also alive. So the claim must be that *human life* is uniquely valuable, in a way that the lives of members of other species are not. Yet against this idea it can be said that it is at least conceivable that somewhere in a distinct galaxy there are non-human life forms that possess value, perhaps even more value, than human life does. Thus, more carefully stated, perhaps the reason we are inclined to regard Baby K differently from Theresa Hamilton is that we think of human life as special, because we stand in a certain relationship, a kind of family relationship, with all living members of our species. We lack this relationship with non-human animals, and with alien life forms. Baby K, who never had or will have any conscious experiences, and does not meet even the most conservative criteria for moral personhood, is nonetheless granted moral standing by us because she is a fellow human being. Thus while Baby K lacks the history of personhood and personal relationships that deceased individuals and individuals in a persistent vegetative state have, she still exerts a moral pull on fellow human beings, because she stands in a family-like relationship with them, a relationship that does not extend to the dead.

This analysis begins to suggest a convergence of ideas. Clearly, we do not and should not treat patients in a persistent vegetative state the same as we treat dead people, such as Theresa Hamilton, who meet the whole brain definition of death. Second, infants born without any capacity for higher brain function have less moral standing than adults in a persistent vegetative state, because they are not past persons and have limited, non-reciprocal relationships with others. The continuum for qualitative futility that emerges looks something like the following:

- conscious patient,
- adult in persistent vegetative state,
- infant with anencephaly,
- brain dead patient.

At one end of this continuum, are patients who are brain dead. Here, we routinely withdraw treatments, such as respirators and tube feedings, and we

do not offer new treatments to family members. For the infant with anencephaly we grant some moral standing because the infant is a live human being. However, this moral standing does not require aggressive life-sustaining treatments, such as emergency CPR.

For adults in a persistent vegetative state, the fact that there was a historical person and past interpersonal relationships makes withholding and withdrawing treatment emotionally difficult for families and loved ones. Meeting the needs of families is an important responsibility of the health professional. However, this responsibility is not unlimited. Thus, it is reasonable to keep a patient alive so that a daughter or son from another state can arrive and say goodbye. It is reasonable to work with family members by providing education and support that helps prepare them for the physical death of a loved one. But unlimited and ongoing support of patients who are no longer persons is not consistent with professional ethics, which is about helping people, not sustaining biological life.

Finally, the case of a conscious patient with an exceedingly poor quality of life is perhaps the most controversial. In cases such as Baby Ryan, we can say at the very least that it is ethically permissible for physicians and hospitals to refuse to offer life-sustaining treatments. Some would argue that in these kinds of cases, it is also permissible for physicians and hospitals to offer life-sustaining treatment, provided families make informed choices and understand the costs and benefits of such decisions.

For all patients, dead and alive, it is important to emphasize the importance of treating individuals with dignity and respect. It would be unconscionable, for example, to fail to provide basic hygiene for a person in a persistent vegetative state (Clayton, 1995). It would likewise be wrong to refuse to honor the wishes of family members to preserve the body of a dead patient until absent family members can say goodbye. For a patient who is conscious and dying, it is imperative to emphasize to the patient and family that the patient will *not* be abandoned and that every effort will be made to provide palliative and comfort care.

Quantitative Futility

While the focus of discussion so far has been on qualitative futility, it is helpful to comment briefly on quantitative futility, which comprises an important part of the futility map. Both cases one and six raise the problem of quantitative futility, and our map of futility would be incomplete without considering this topic. At one end of the quantitative futility spectrum are cases where we possess a high degree of confidence about the likelihood that a treatment will fail, based on data collected from large samples of other

patients. For example, in Case One, the evidence from studies such as Bedell and colleagues showed that no patients with pneumonia or metastatic cancer survived to hospital discharge after CPR. Thus we can say with a high degree of confidence that CPR will not benefit the patient. Are there exceptions? As noted already, we can imagine a situation where a patient may wish that everything possible be done to keep her alive for a limited period of time so that her daughter from another state can come and see her and say goodbye. This was not the scenario in Case One. In this case, the patient's family was present, and the request for a full CPR effort was not made on a short term or temporary basis.

Further along the continuum of quantitative futility are cases where data from controlled clinical studies is lacking and physicians rely on their extended experience as the source of their conclusions. Here, specialty practice contributes an essential element. For example, an intensive pulmonary specialist who sees several hundred patients who have similar disease conditions and receive similar therapy can often group together "futility characteristics" better than a generalist who does not see cases in so focused a manner.

At the far end of the spectrum are cases where empirical studies and clinical experience are lacking, or are insufficient because a treatment is novel or experimental. There may be a great deal of hopefulness surrounding a novel or experimental treatment. It may be thought, for example, that the mere fact of doing something means that success is more likely. Or it may be thought that new interventions are more likely to succeed than fail (Schneiderman and Jecker, 1996, p. 250). Yet these beliefs lack empirical support (Altman, 1993).

The continuum for quantitative futility that emerges looks something like the following:

- Empirical evidence from clinical trials establishes that a treatment will fail (>99% odds).
- Clinical experience with patients who have similar disease conditions establishes that a treatment will fail.
- Little or no evidence exists about whether a treatment will succeed or fail because it is novel or experimental.

This continuum helps us to understand that not all cases of low likelihood of success are the same. Someone who is perfectly comfortable not offering a treatment that has been repeatedly shown to fail in controlled clinical trials, for example, may be less comfortable relying on the judgment of an experienced physician, unless she knows and trusts that person's judgment. Likewise, someone who is comfortable with withdrawing or withholding interventions that are quantitatively futile in the first two kinds of cases, may

be less clear about how to respond in the case of a novel or experimental intervention.

In general, we can say that where there is strong empirical evidence that a treatment will fail in 99% of cases, physicians should not offer or continue it. Thus, in Case One, physicians have strong ethical backing for not offering CPR to the woman with myelogenous leukemia and pneumonia. Case Six, by contrast, relied on the extensive experience of specialty physicians. Multiple specialists were involved in the care of Ryan Nguyen, the premature infant born with multiple medical problems, including kidney failure, bowel obstruction, and brain damage. According to one consultant, a professor of pediatrics and director of the kidney program at Children's Hospital and Medical Center in Seattle, "long-term dialysis would not only be inappropriate, but would be immoral...it would prolong pain and agony in a child that has no likelihood of a good outcome" (Dr. Ellis D. Avner quoted in Kolata, 1994). This remark shows that what is at stake is not only a poor likelihood of survival (quantitative futility), but also the poor quality of outcome to be achieved (qualitative futility).

Were physicians wrong about judging life-saving interventions futile in the case of Ryan Nguyen? In addressing this question, we can think about quantitative futility as marking a point along a probability continuum at which the likelihood of benefiting the patient is exceedingly poor. As noted already, when the chance that an intervention will benefit the patient is less than 1 in 100, we can say that it offers no significant benefit and is quantitatively futile. This threshold is not arbitrarily chosen, but instead appeals to the notion of reasonableness. As my colleagues in empirical research point out, in controlled clinical trials when treatment observations are compared against the null hypothesis, any observations associated with treatment that occur in only 1 in 100 cases (or fewer) do not rise to the level of "significance" because they could have occurred at random rather than being caused by the treatment. If a treatment is futile in the quantitative sense, patients receiving it will occasionally get better, just as random events occasionally occur, but it is reasonable nonetheless to say that the treatment does not provide a significant benefit to a population of patients. Ryan, for example, did better than expected. Yet the vast majority of babies in his situation will not do well. Moreover, if institutional policies routinely sanctioned futile treatments, they would condemn many patients to suffer needlessly. For this reason, general standards of medical practice require *justifying* the use of painful and invasive technologies by showing that they hold reasonable prospect of helping the patient (Jecker, 1995).

Physicians who refused to provide life-sustaining treatment for Ryan were not acting arbitrarily. Instead, they based their conclusions on extensive

experience caring for infants in Ryan's situation who failed treatment. While we may feel somewhat less comfortable judging futility on the basis of clinical experience compared with controlled clinical trials, both kinds of cases are marked by uncertainty. In other words, there is always a chance that a treatment that has never worked in the past (either in studies or observations from clinical practice), will work the next time. Because medicine is an inductive and probabilistic science, we can never be certain (as long as a patient is alive) that a treatment will fail. The distinction between cases one and six is one of *degree*, not a difference of kind. In both cases, physicians are justified in not offering futile interventions to patients and families.

What about the case of experimental or novel treatments? If there is no evidence that a treatment will work, does this mean it is futile? Are doctors obligated to offer interventions in the absence of evidence that they will help the patient? In response to the first question, it can be said that experimental treatments are not the same as medically futile treatments. Whereas futile treatments empirically fail to demonstrate a significant probability of benefiting the patient, experimental treatments have not failed. Instead, we simply lack sufficient empirical evidence to say whether they will succeed or fail. In the case of experimental therapies, there may be promising but insufficient evidence. Thus, experimental therapies are worthy of further investigation. Are doctors obligated to offer experimental treatments? With futile interventions, it was the overwhelming evidence of failure that lent support to the idea that the intervention should not be offered. But experimental therapies have a high degree of uncertainty. Elsewhere, I have argued (with my colleague, Lawrence Schneiderman) that although many members of the medical profession feel pressured to provide experimental treatment on demand, such treatments are not ethically obligatory. Patients undergoing novel or experimental treatments should be protected by the appropriate institutional review board that monitors human subject research, and should clearly understand that a promising treatment may be just as likely to hasten a patient's death, or make a patient more miserable, as it is to save a patient's life or improve its quality.

In summary, we saw previously that qualitative futility raised the question, How poor does the quality of outcome have to be to qualify as futile? We can now see that quantitative futility raises a similar kind of question, namely: How low does the likelihood of benefiting the patient have to be to qualify as futile? In response, we can say that the lower the likelihood of success, the more comfortable we are in saying that an intervention is medically futile. People may disagree and argue about where the specific threshold for quantitative futility lies. Some may think a 5%

chance of success is futile, rather than the 1% chance my colleagues and I have proposed. However, all could agree with the more general idea that at some point the likelihood of success is so slim that the intervention is futile. Moreover, the lower the likelihood of success, the greater the ethical justification is for withholding or withdrawing the treatment. Where we can say with confidence that there is less than one chance in one hundred of benefiting the patient, I have argued that treatment should not be offered.

Comparing Schiavo and Quinlan

Let us return now to the case of Theresa Schiavo with which we began. Like Karen Ann Quinlan and Helga Wanglie, Theresa Schiavo is in a persistent vegetative state. Like these patients, she is receiving life-prolonging interventions, which are producing a desired physiological effect. Artificial nutrition and hydration is effective in nourishing and hydrating Theresa Schiavo's body. Yet does it accomplish any goal of medicine? It has never been a goal of medicine to sustain biological life without consciousness. Instead, medicine has always existed to help people. Will Theresa Schiavo ever experience any benefit from artificial nutrition and hydration? Clearly not.

We have seen that on a qualitative futility continuum, we regard patients like Theresa Schiavo as having more moral standing than a brain dead patient or than an infant who is born without any higher brain. I have argued that our different responses may spring from the history of personhood and personal relationships with someone who once had higher brain function. It also may be based on the fact that we have a special regard for living human beings, with or without higher brain function, because they are fellow human beings. This helps to explain the psychological turmoil that attends the removal of life support from patients in Mrs. Schiavo's situation. Although life support is qualitatively futile for a patient in this condition, there is a tremendous difficulty involved in the process of stopping life support. Despite this difficulty, I have argued that there are ethical reasons to terminate treatment and allow death to occur in cases like this. First, assuming the diagnosis of persistent vegetative state is accurate, we are not dealing with a moral person in the strict sense, because Theresa Schiavo lacks morally necessary qualities, such as conscious awareness of her self and her environment and the ability to interact with others. She also lacks the potential to regain these capacities in the future. Second, we are not dealing with a moral person in the broader social sense, because Mrs. Schiavo is not capable of interpersonal relationships. Instead, Theresa Schiavo is considered to have moral standing on the basis of her past personhood and

past moral relationships, and on the basis of her membership in a human community. Yet these grounds do not establish that Mrs. Schiavo has a moral right to life, as a moral person does, but instead establishes that she deserves to be treated with dignity and respect. It is ethically permissible to refrain not only from nutrition and hydration, but also from other life-sustaining measures, such as antibiotics to treat an infection, should one occur, emergency CPR and ventilator support should she experience respiratory distress, or vaccinations to prevent flu, which could very well be deadly for a patient in this condition.

The issues that patients such as Theresa Schiavo raise will continue to challenge our moral commitments, because they raise deep and foundational questions about who has standing and membership in our moral community. Despite the ongoing challenge such cases present, I have tried to advance the idea that we have made significant progress as well. In our reasoning and response to cases involving medical futility, we make a number of important distinctions. Rather than lumping all such cases together, we instead distinguish between quantitative and qualitative futility, and then make further distinctions within each category on the basis of moral similarities and differences. These groupings are not merely conceptual. Instead, they give us a moral map, and the reasoning associated with different case families gives us a moral compass. While a compass does not indicate precisely what turns to take at each and every street, it does point to a general direction, suggesting which way we need to go in a broader sense. In the case of Theresa Schiavo, neither a longer life nor more life-sustaining technology should be the goal of medicine.

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