Monotheistic Faith Perspectives on Brain Death, Do Not Resuscitate Orders, Patient Autonomy, and Health Care

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Dr. Khan: First, I wanted to share with you three personal experiences regarding this topic.

My first experience with death occurred at my home in Kashmir when as a medical student I was asked to evaluate my father's mother because she did not look well. I put a cotton strip under her nose; there was no movement. I put the stethoscope to her chest; there was no heartbeat. I announced that Grandma had passed away. Peaceful death in the home setting, surrounded by family and friends, is still a common scenario in the developing world.

Now let us fast forward to the 1990s. As Chief of Medicine at Nassau County Medical Center, I was called to consult a family in New Jersey. A patient in her late 70s was in an intensive care unit, on pressors, on mechanical ventilation, and being monitored. She had had a massive cerebrovascular accident, and her six prosperous adult children were at her bedside. It was clear to me that she was brain dead, and I suggested to the family that further intensive care unit (ICU) care was pointless and futile. One of the daughters challenged my assumptions stating: "We can see the heartbeat on the monitor, the bag is full of urine, her skin is warm, so how can you make this pronouncement?" Of the six siblings, three agreed with my recommendation to stop ICU care, and three declined. She continued to stay in the ICU for another week or two and finally "died" when her heart stopped.

Our dilemma in the United States is that technology has advanced very quickly, while society has not kept up with the pros and cons of utilizing advanced technology. This results in the types of conflicts this patient's story illustrates.

The third case was at Nassau County Medical Center, Nassau County, New York. We had established a chronic ventilator unit where we put patients who had a poor quality of life and had little or no hope for meaningful recovery. The staff provided tender loving care. While serving as the consultant on this unit, the son of a patient approached me and said, "It does not look like mother is going to recover, so why don't you just discharge her?"

I said, "Fine, if you want to take care of her at home." A few weeks later she died. The son thanked me and was appreciative as his mother had experienced very comfortable end of life — "good death" — surrounded by her children and grandchildren.

Controversies surrounding end-of-life issues exist and are likely to get worse. One of the major questions that patients, providers, and policymakers shy away from is: how much health care should they provide and at what cost? In the early 1900s life expectancy in the United States was 47 years, by 1950 it had climbed to about 68 years, and now it is

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almost 78 years. The longer we live, the more health care we consume, and that costs lots of money. Some scientists are predicting that the aging process can be conquered. In the United States, 30% of healthcare dollars are spent during the last year of a person's life and much of it in situations where the patients' quality of life is very poor. It would indeed be a great irony if after spending a huge fortune, the life expectancy reaches a 100-, 150-, 200-year mark, and in the process we have bankrupted the society and are unable to afford the care needed.

Americans are treated at increasing levels to the time of death, spending more time in hospitals in their final days and racking up bills, a combination that has made medical care the leading cause of bankruptcies in the United States. More than 80% of the people who die in the United States have had long progressive illnesses such as cancer, heart failure, or Alzheimer's. Eighty percent of such patients say they want to avoid hospitalization and ICU care when they are dying. There is growing evidence of increased hospitalizations during the last six months of a person's life. From the pool of Medicare patients admitted to hospitals, increasing numbers end up using high-cost ICU services. Data from Medicare shows that in 1966 there were 1,300 ICU admissions per 1,000 Medicare patients. Now there are more than 1,400 per 1,000. Treating chronic illness in the last two years of life consumes nearly one-third of all medical costs. One large study of Medicare records found that nearly 14% of cancer patients who died in 1999 received chemotherapy in the last two weeks of their lives. Data regarding Medicare costs and utilization of services by region, hospital, and state are available at the Dartmouth Atlas (dartmouthatlas.org).

In this panel, we will, from the Abrahamic faith perspective, address four questions based on real cases.

First: Is brain death accepted as a definition of death?

Second: Can a patient write advance directive and do not resuscitate (DNR) orders?

Third: How to break bad news and how much information to share with the patient, particularly if the family requests "shielding" the patient from bad news?

Fourth: Who pays for the cost of expensive futile health care, as illustrated by the case of Terri Schiavo, a young woman who remained in a persistent vegetative state (PVS) for 15 years? Is the family responsible or is society? Can and should we do everything for everybody?

Let me briefly introduce our panelists:

Rabbi Jerome Davidson served at Temple Beth El in Great Neck, Long Island, New York, as the chief rabbi for more than 40 years. He retired in 2007 after having held numerous leadership positions in the Jewish community, locally and nationally, including the president of the Synagogue Council of America. I have known Rabbi Davidson for 20 years, and my interaction with him started with one of his programs, which he initiated, called American Muslims and Jews in Dialog, which has been a model now in the country. Rabbi Davidson is on the faculty of the Hebrew Union College in New York, teaching a social responsibility course to rabbinic students.

Dr. Fredrick Smith has a very interesting career. Having been a senior attending in the Department of Medicine at North Shore University Hospital since 1993, he now has decided to get trained again. Currently, he is a fellow in bioethics at the North Shore Long Island Jewish Health System. Dr. Smith grew up in Colombia, South America, where his parents were missionaries. He returned to the United States, attended college in Wheaton, Illinois, and graduated with a degree in history. He spent one year of theological education at Yale Divinity School. Nine years later he decided to enter medical school. He graduated from State University of New York (SUNY) Downstate College of Medicine. I have known Fred when he used to bring the medical residents to the Islamic Center of Long Island so that he could provide them an opportunity to experience different faiths and address their questions and concerns. A few years ago, after being a consultant for many years, Fred switched from care of hospital inpatients in both geriatrics and palliative medicine and decided to enroll in a fellowship program to study medical ethics. This year he has become an ethics consultant for North Shore under the guidance of Dr. Sam Packer, who is one of our speakers in this conference. Fred is also participating in development of the curriculum for the Hofstra Medical School, which Dean Firestone talked about. Dr. Smith is a member at Christ Episcopal Church in Garden City, where he has taught Sunday school.

Professor Gamal Badawi is a professor emeritus at St. Mary University at Halifax, Canada, where he has taught in the areas of management and religious studies. After retirement, he still teaches courses in Islam on a part-time basis. He is a prolific speaker and writer. His audiotapes and videotapes have been a source of guidance for many of us in learning about our faith, Islam. I had the pleasure of sitting on the same board as Dr. Badawi at the Islamic Society of North America, and let me tell you when Dr. Badawi speaks, everyone listens. That is the kind of respect he has held in the community.

Let me finally briefly introduce myself. I was born and educated in Kashmir. I am an internist-pulmonologist and have published extensively, including three books, more than 150 articles, and several hundred presentations. I was the first international medical graduate Regent of the American College of Physicians (ACP) and received the New York State ACP Laureate award in 1998. I served as chief of pulmonary medicine at Queens Hospital Center in New York from 1977 to 1986, chairman of medicine at Nassau County Medical Center from 1987 to 1999, and as a consultant at King Fahd Medical City (KFMC) in Riyadh, Saudi Arabia, from 2005 to 2011. I served as president of Islamic Medical Association of North America (IMANA), member of its board of regents, and I am an associate editor of the Journal of Islamic Medical Association (JIMA).

We will be hearing about Islamic ethics and the five core elements that form the basis of Islamic ethics: preservation of life, faith, mind, possessions, and parentage. These are the core values, which I am sure Dr. Badawi will elaborate on further. The scriptures tell us that God gives cure, we are just messengers, for the ultimate cure is from the Creator. We are also are told, as Dan Varisco mentioned in his earlier presentation, that individuals are encouraged to seek treatment.[1]

Let us start with brain death. All these are real cases from Saudi Arabia. The discussions we have here in Nassau County, New York, are very similar to the discussions held in the critical care units in the Middle East. I am particularly thankful to my colleague at KFMC, Dr. Hani Lababidi, who provided the three case studies that I will present for discussion.

Case History 1: Is brain death acceptable as the definition of death?

Mr. X is a 28-year-old male teacher who was previously healthy. He was found in his home, unconscious in his bed. His family gave a history of generalized tonic-clonic movements the evening before. The unconscious patient was transferred to a nearby hospital. He was intubated and attached to mechanical ventilation. A computed tomography (CT) scan of brain revealed "diffuse subarachnoid hemorrhage with brain edema, a nonenhancing hypodensity in the right frontal lobe." The patient was transferred to a tertiary center for further management.

The patient at this stage had stable vital signs and was on nasogastric feeding and intravenous fluids. On the third day, the patient developed fever and intolerance to nasogastric feeding. The primary physician asked for a septic screen, began empirical antibiotic coverage intravenously, and ordered parenteral nutrition support. The intensivist objected to this treatment plan as he believed the patient is already brain dead. After discussion the primary physician clearly mentioned that he "does not believe in brain death."

A family meeting was convened in the presence of the primary physician, an internist, and the patient's father, who was in denial and asked for second opinion. A team of physicians from another medical center — a neurologist, neurosurgeon, and an intensivist — reviewed the case and confirmed brain death. The father refused their decision. The organ transplant team was consulted to approach the father, but he refused to meet with them.

Rabbi Davidson: I would not have assumed years back that I would end up a few hours before the beginning of the holiest day of the Jewish year speaking about this subject to a medical society, but it is an honor to do so. I cherish my friendship and work with Dr. Khan over quite a number of years. It has been very gratifying for our Jewish community indeed to share close friendship with the Islamic community that he has guided.

The question that is asked is: "Is brain death acceptable as a definition of death?" is probably not the question to which the Jewish tradition would respond, but the response will become fairly clear after what I will outline, not at great length, as the basic principles that are involved. They apply as well to the other aspects of the discussions that we are going to have.

There are two major principles within the Jewish faith regarding the whole question of end-of-life decisions. One is a commitment to the sanctity of life. Life is key to everything that Jews believe in. While there are a variety of beliefs within Judaism about what happens after we die, it is clear that the major emphasis is on this side of the grave. There is sanctity about life that is so strong that the taking of life is the most unthinkable of all acts that can be performed. In fact, on the Day of Atonement, we read from the Torah text, Moses' final speech to the children of Israel. In it he says "Choose life and blessing, not death and the curse."

Second, the laws with regard to all kinds of rituals, whether about the Sabbath and its sanctity or even Yom Kippur, the holiest of days, all the prohibitions are set aside if there is the possibility of what is called in Hebrew *Pikuach Nefesh*, the saving of a life. Every effort is made, even if it means breaking the holiest of codes, and almost anything is set aside in order to save a life. When I say almost anything, one is not allowed, of course, to kill somebody else in order to save another person, but is certainly encouraged to break whatever ritual commandments in observance in order to go out and to perform a saving action. Even more, if you do not act when there is an opportunity to save a life, you are held guilty within the Jewish tradition of "standing idly by while your neighbor bleeds," which is taken from the Biblical book of Leviticus in the Hebrew Bible that you are familiar with. So there is a command, a clear command of life, and one who is dying is nonetheless to be considered alive. One is not allowed to ignore the needs of that individual.

However, there is another very important principle that must be set next to the principle of life's sanctity, and that is the principle of compassion. It really provides us with the key to understanding the Jewish tradition in this entire issue of end-of-life ethics. This principle is reflected in a story that appears in the Talmud, which is a rabbinic set of volumes of laws and ideas that is post-Biblical and probably written during the first and second centuries before the common era, up through perhaps the fifth and sixth century CE. It constitutes the accumulation of laws and discussions in the ancient Jewish academies.

The story is of the great Rabbi Judah Hanasi, Juda the Prince, a great scholar who helped to create a part of the Talmud, which is revered by all. When he was dying, he was in great pain, but his students, who loved him, prayed constantly, without a break, to God to keep him alive. In this story, a woman servant of Judah Hanasi saw the rabbi suffering and the students praying. The assumption was that prayer had efficacy and was literally keeping him alive. She went up to the roof of the building where Judah Hanasi lay and took a pottery vessel and threw it into the courtyard where the students were praying. It crashed and startled them, and they stopped praying for a moment. Judah Hanasi died.

The story is told with approval, and the maid servant who performed the act is lauded by the teller of the story and subsequent repetitions of it. So there you really have it. You need not, the story would teach us, do what would keep a person alive if they are suffering and there is no hope for any kind of improvement of health and renewal. That really is the basis of the Jewish law. The Talmud goes on to say that if, for example, someone is chopping wood and the rhythm of the chopping of the wood is somehow within the hearing range of the dying person and keeping that person's mind riveted, you could stop the chopping of the wood, in order that the person would die. Or if the person has salt on his tongue on which he is concentrating and aware of it, you can remove the salt because then the person will expire. Of course these are unscientific, but the truth of the matter is they do very much relate to modern time. What you are not allowed to do, the Talmud says, is to close the person's eyes to hasten his dying. You are not allowed to take his pillow away to hasten his dying. The conclusion really is that when a person has reached the point where there is no hope for any kind of return of health, and there is suffering and pain, it is permitted to remove the impediments to death.

What is not permitted is to take an active role in hastening death. It is not permitted to do something that would kill a person through an act that one performs, but one can remove that which is simply preventing the process of death from occurring. Therefore, when we get to the issues of brain death or persistent vegetative state, which are medical issues that I of anyone in this room have the least understanding, it becomes clear that when there is no hope, it is permissible to cease artificial ventilation, tube feeding, and water feeding if the person is just being kept alive in a state that is not really living at all. On the other hand, what would not be permitted would be the injection of some kind of medication that would hasten death and be done particularly for that purpose.

There it is, not so much a question whether brain death means death but how one treats a person who has no hope of recovery and who is clearly being kept alive by artificial means. The answer that most Jews, and that the largest part of the Jewish community of scholars, would accept is basically to remove the impediments to death.

With the Terri Schiavo situation, some of the Orthodox scholars felt that feeding through tubes was the normal process. The person was eating and therefore, to take that away would be an act that would bring about death, and they were reluctant to do it. The vast majority of scholars, Reform and Conservative, and some Orthodox, felt that because the person was not swallowing, which really constitutes eating, the nutrients and the water were simply in the same category as medicine, which can be withdrawn if it is an impediment to death. There are gray areas, but essentially that is the Jewish position on this question.

Dr. Smith: Although I confess to being a Protestant — a rare species on Long Island — much of what I say today will be based on Roman Catholic thinking. Catholic scholars have a very long tradition that is almost as long as the Jewish Talmudic tradition, and only a few hundred years longer than the Islamic legal traditions. It is unfortunate, in my view, that my tribe, the Protestants, decided in the 1500s that the previous thousand-plus years of tradition could be thrown out the window, causing us to sort of start over. When I review the literature of evangelicals — the religious culture I grew up in — it appears to me as though the authors reinvent the wheel every time they address an issue like this one. However, I will also try to take account of traditionalist views of both Protestantism and Catholicism, because I think that these perspectives have a great influence on what is happening in our country, politically and socially, with respect to health care at end of life. In 2009 the plan to pay doctors to discuss advance directives with Medicare patients was suppressed when some politicians — claiming the mantel of evangelical "Christian family values" — accused those who were crafting the health reform "Affordable Care Act" of creating "death panels." I admit that, as someone who chose to align with the "mainstream" Anglican tradition, my views are more liberal than those of some of my evangelical relatives.

Nevertheless, I believe that all Christians — regardless of denomination or tradition — would agree with Rabbi Davidson about the sanctity of life, a value that goes beyond the four normative ethical norms and other moral dimensions outlined by Beauchamp and Childress over more than three decades: autonomy, beneficence, nonmalficence, and justice.[2] These four principles find space in all the Abrahamic religious traditions and, one could argue, stem from core values in our traditions. I think those of us who are observant Jews, Muslims, or Christians are influenced by a belief in the sanctity of life when we approach end-of-life dilemmas in bioethics

In terms of brain death, the fundamental pertinent perspective in Christianity has to do with our conception of personhood, which is largely derived from the Hebrew scripture. We are all "people of the book"; my parents taught me very early on to love the Bible. I have it with me. In the first biblical book and chapter — Genesis 1:26 and following verses — the ancient Hebrew chronicler tells how the human species emerged in the Creation:

> Then God said, 'Let us make man in our image, after our likeness; and let them have dominion over the fish of the sea, and over the birds of the air, and over the cattle, and over all the earth, and over every creeping thing that creeps upon the earth.' So God created man in his own image, in the image of God he created him; male and female he created them. And God blessed them, and God said to them, "Be fruitful and multiply, and fill the earth and subdue it." . . . And God saw everything that he had made, and behold, it was very good. And there was evening and there was morning, a sixth day.

Human beings are said to have been created in "the image of God." Therefore, Christians believe that all humans are bearers of the *imago dei* (the Latin term for the image of God), which the Creator chose to imprint in all members of this specially chosen animal species, *homo sapiens*.

There seems to be broad agreement among non-religious and most religious people that the specialness of a person resides in the human brain, without which there can be no thoughts or emotions or relating. Once the whole brain is dead — not only the cerebrum and cortex, but also the lower, more primitive brainstem, which we share in common with other animals — then the person is dead.

Brain death as a "diagnosis" is an artifact of modern technology. Because there is no spontaneous respiration when the brainstem does not function, apnea is one of the critical clinical criteria for brain death. However, the cardiovascular system may maintain independent function for a few days after death of the brain. Thus, the clinical construct called "brain death" became possible only after the invention of mechanical ventilators to sustain life after respiratory failure, and after development of medications, for example, strong pressor medications that raise blood pressure, antibiotics to fight infections, etc. The whole issue of defining and declaring brain death arose when organ transplantation became an option and when it was obvious that most available organs would not come from live donors. Because individuals whose brains did not function — in terms of spontaneous respiration or reflexes dependent on brain pathways — could still maintain cardiovascular function and organ perfusion, for a period of days, in an intensive care unit, these individuals could provide a source of still-functioning organs to replace malfunctioning organs in living people with intact brain function (and hence personhood). This led to development of consistent criteria in states such as New York to regulate the declaration of brain death, so that the brain-dead person in the ICU, whose visceral organs were still nourished with oxygen and blood, could become an organ donor.

Christians have had little, if any, difficulty with this concept, because a person whose brain is dead can no longer express the *imago dei*. This is true even for the National Association of Evangelicals, a very conservative organization. Roman Catholics have not objected to the current definition of brain death.

Persistent vegetative state (PVS) — when the cortex is dead, but the brainstem is working — has raised new questions since the Terri Schiavo case, at least with respect to artificial nutrition and hydration through a feeding tube. If a person is in a vegetative state, with spontaneous breathing and eyes that can open and gaze that can roam, personhood may still seem recognizable and the image of God may appear to be there in a way that is not possible when the brainstem is gone. A person in PVS reminds us to refocus on the sanctity of life, the dignity of the living human being. Just as we all worry about withholding treatment from people who are disabled or handicapped, I can appreciate that to stop feeding a person in PVS may look like too slippery a slope. But brain death does not seem to present a similar problem.

Dr. Badawi: First, sanctity of human life is something that joins together Jews, Christians, Muslims, and secularists or any other person with good sense. Second, sanctity of life means that you do not take the life of a human being without any due right, even with the motive of compassion for the suffering of that person i.e., active euthanasia. Sanctity of life also implies that we are duty bound to not take life unjustly, but also to save life. In fact, as Dr. Khan was listing the supreme objectives of Islamic Sharia'h, and next to preservation of faith is preservation of life. Muslim jurists actually say saving life does not necessarily mean not killing a person, but providing the person with the needs necessary for life. These necessities, include the right to be saved when in danger (e.g. when drowning or in house on fire). They include also the right to have food, clothing, and shelter. All of these concepts are summed up in the Qur'an in confirmation of what was revealed to previous prophets

> On that account: We ordained for the Children of Israel that if anyone slew a person — unless it be for murder or for spreading mischief in the land — it would be as if he slew the whole people: and if anyone saved a life it would be as if he saved the life of the whole people. Then although there came to them Our Messengers with clear Signs, yet even after that many of them continued to commit excesses in the land.[3]

Complete, certain, and irrevocable brain death as determined by competent medical experts is an acceptable definition of death and does not contradict principles and rules of Islamic jurisprudence. A crucial decision in the matter of life and death is best arrived at with the participation of medical doctors and other concerned parties. This is based on the fact that the traditional definition of death as cessation of heart beats has become imprecise in view of modern medical technology. It must be certain that there is absolutely no hope or possibility of returning back to life. In such a case, the person is deemed dead, and there is no need even to consider keeping life support equipment because there is no life to support in the first place. However, it is permissible to continue life support if such equipment is used to keep the body warm so as to retrieve a donated organ in a usable state that might save the life or mitigate the suffering of a potential recipient.

Case Study 2: According to your religious beliefs, is it acceptable to have a DNR or living will ?

Mrs. X is a 70-year-old female with advanced pulmonary fibrosis. She is home bound in Riyadh, Saudi Arabia, and has been on home oxygen for the past two years. She was brought to the emergency room (ER) because of an increase in dyspnea and oxygen requirement. In the ER, she was fully awake and oriented. There was no evidence of new pneumonic infiltrates. She was placed on oxygen mask 50% FiO2 with oxygen saturation by pulse oximetry reaching 92%. Echocardiography revealed severe pulmonary hypertension and diastolic dysfunction. Despite optimizing antihypertensive medications and diuretics, the oxygen requirements remained high.

The patient lives with her son who is retired from the military. She has another son living in Jeddah and three married daughters. Her youngest daughter is a pharmacist and remained with her mother in the hospital.

In view of her end-stage lung disease, the primary physician, a pulmonologist, the cardiologist and another pulmonary consultant signed a DNR order. One week after admission, the patient had increased dyspnea and tachypnea. The daughter asked the primary physician to transfer her mother to the ICU.

Dr. Badawi: A living will and an advance directive such as a DNR are permissible measures according to Islamic scholars. In fact, we heard this morning about the question of patient autonomy, which may include the terminal patient's desire to continue treatment or to die in peace. The issue of the obligation for a person to seek medication or treatment has been long debated. As early as the 11th century, the famous scholar abu Hamid al-Ghazali summed up the argument for which we call today the patient's informed autonomy. He refers to some of the Ahadith (sayings of Prophet Muhammad ﷺ), which indicate that a Muslim is encouraged to seek medication when he or she falls ill and that God did not create a disease without creating a cure for it. He also cites references to statements and actions of some of the companions of the Prophet ﷺ who refused medication and chose to focus on the desire to seek forgiveness of their sins. In summing up his opinion at the end, al-Ghazali said that in situations where medication is known to be effective, it should be used. But, prophetically, he said also that in situations where medications (other therapies) are not that effective and are likely to prolong pain, there is no obligation to use them. I think that view seems to balance the arguments of both sides. Some contemporary scholars such as al-Qaradawi adopted the same opinion as al-Ghazali. With this in mind, and based on the notion of informed patient autonomy, it is not a sin for the terminally ill patient to say "I do not want to be treated. I wish to die at home. I do not want to have that uncertain or ineffective therapy." A problem may arise, however, if the patient did not have a living will or advance directive and reached a stage where he or she became incapable of making an informed choice. Based on the criteria of definitive brain death discussed earlier, it is possible for others to deem that the person is dead and may act on his behalf in what they see as his or her best interest. The problem, in the context of North America and maybe other societies, is the possibility of differences of opinions between members of the patient's family as we saw in the Terri Shiavo case when the issue turned into an issue of law (and possibly politics too)

The only thing that I can add here, which I learned from Dr. Faroque Khan, who is commuting between the United States and Saudi Arabia, is that in Saudi Arabia, there has been a fatwa (religious opinion) that requires a committee of three licensed physicians to examine each specific case, and if all agree that continued use of life support equipments is futile, they may sign a DNR, and the equipment may be unplugged.

Dr. Smith: A central theme in Christian faith is the death and resurrection of Jesus Christ and the promise they provide of eternal life for Christians. Death is sometimes seen as a passage to a better life, to eternal life; one is "going to God." The Apostle Paul, when he was contemplating the potential for his own execution in Rome, said that he was wrestling between, on the one hand, a duty to remain in the world and be a leader to the struggling early churches; and, on the other hand, his desire to be with Christ. At one point he said "to be absent from the body is to be present with Christ." So, the Trinitarian doctrine that God personally manifested in Christ creates faith that our death — like Jesus' death — leads to eternal life. This hope that softens our fear of death and gives us some comfort in the face of our inevitable mortality. Therefore, in a sense, death is not an enemy; yet elsewhere in our scripture, St. Paul himself says that the last enemy to be defeated is death. As human beings, we are obviously ambivalent; even though we are not "supposed" to be afraid, we are afraid, and that is part of our genetic make-up.

From a spiritual standpoint, however, death is not the end: God is sovereign, God is gracious, and God will take care of us, so death need not be feared. Nevertheless, when I was a palliative care doctor, I often found that conservative Christians, particularly from the evangelical tradition I grew up in, often had great trouble accepting palliative care, in spite of their faith in eternal life. It sometimes puzzled me that people who expressed such eagerness for Heaven seemed to have such trouble allowing a terminally ill and comatose patient to leave this planet.

On the other hand, Christian faith celebrates the material Creation and places a high value on preserving sacred life in this world. Pope Pius XII distinguished between "ordinary" and "extraordinary" means of sustaining life. A treatment that commonly or "ordinarily" protects your health and prolongs your life should be accepted. There is a duty to maintain one's life through common medical measures. If an antibiotic is going to cure your pneumonia, is easy to get, and is not going to bankrupt you, you should buy it and take it. On the other hand, maintaining life on a ventilator in the face of severe lung disease and recurrent pneumonia is an "extraordinary" medical measure. This is where the principle of proportionality must be applied. After weighing duty to live against the burden of the means of living, a patient may legitimately choose to stop burdensome mechanical ventilation. The Catholic doctrine on which this permission is based goes back about 500 years. Because some people were obviously too poor to access the kind of medical care that might keep them alive, the Church taught that such people were not required to cross land and sea or to impoverish their families or communities in order to obtain a costly treatment that might keep them alive. Proportionality is thus very important and central. Following are the latest ethical religious directives for Catholic Healthcare Services, issued by the United States Conference of Catholic Bishops and reflecting a few changes that were made after the Terri Shiavo case. The first short directive number 56:

> A person has moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the judgment of the patient offer a reasonable hope or benefit and do not entail an excessive burden, or impose an excessive expense on the family or the community.[4]

It does not specify precisely which medical interventions are ordinary, and which are not. Discerning the difference is what the person must pray over and discuss with family and clergy. Those discussions may differ from what the bishops contemplated or from a conclusion a bishop might reach in the particular case. There is room for individual conscience.

I think that burden, particularly when you see the expense for family and community, even has implications for the issue of distributive justice, which we might get to in the Schiavo case.

The next directive is number 57:

> A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope or benefit, or entail an excessive burden, or impose excessive expense on the family or the community.[4]

Here we have the mirror image. One excessive burden may be that focusing on relatively futile "extraordinary" medical interventions gets in the way of spiritually preparing for death. Again, the Catholic bishops' directive says: "Use of life-technologies is judged in light of the Christian meaning of life, suffering, and death."[4] The passion of Jesus Christ is the climactic story in the Christian Gospels. In some sense, Christians are asked to take "the way of the cross." We are told that life has its burdens; life has its crosses; life has its suffering. Not only can we not totally avoid these things, in some way we are called to embrace them. At the same time, we also have to act proportionately to limit suffering.

The Catholic bishops conclude: "Institutions offering care to persons in danger of death, from illness, accident, advanced age or similar conditions, should provide them with appropriate opportunities to prepare for death... . They should be provided the spiritual support as well as the opportunity to receive the sacraments in order to prepare well for death."[4]

If aggressive medical care is not going to help much but consumes all mental and psychic attention as patients and families "watch the numbers," life-sustaining treatment can certainly be an obstacle to preparing spiritually for death. Going to the ICU and becoming irreversibly dependent on a ventilator is a pretty sure way of creating barriers to getting the spiritual support you need at end of life. On a ventilator, the patient usually needs sedation, and is generally no longer capable of spiritually preparing for death.

Christian preparation for death may involve reconciliation with estranged family members or friends or receiving the Eucharistic communion, the bread and wine that symbolize the passion of Christ and the call to human beings to be with God and with each other. For the Christian, the purpose of life for human beings, is centered on restoring communion with God and with each other. Because offending others, or taking offense, seems to be an inevitable part of the human condition – one of the aspects of the "original sin" St. Augustine said we cannot escape – we all have people to reconcile with. Forgiving and receiving forgiveness are, I believe, central aspects to preparing spiritually for death. Restoring relationships is a way of healing some of the wounds we might otherwise leave behind among the people we have loved. Reconciliation prepares us to meet God, whom we Christians believe is ultimately the source of our personhood and capacity to live in relationship, the One whose love for us allows us to love and to live in union.

Rabbi Davidson: I was very interested in the comments of my colleagues. Of course, in the Jewish faith, there is a concern about helping people face the end of their lives, and as a matter of fact, the lessons of reconciliation, atonement, the importance of family, and the importance of sharing the deepest part of our lives with those who are dearest to us is not just an end-of-life issue; it is something that goes on in the Jewish faith throughout life. I think in this particular day that begins this evening, the Day of Atonement, Yom Kippur, for Jews is a reflection of precisely what has just been indicated in Christian terms. The difference is, however, that there is no sense in any place in Judaism that death is going to take us to a better place. I do not think that really is a part of Jewish thinking.

Certainly there are within Judaism, I inferred it earlier, many concepts about immortality through the love that we have shared that remains, immortality through the work that we do, immortality of our soul being bound up with God in a way that we cannot spell out and do not truly, of course, understand. We do not believe that anything as precious as the human spirit just perishes, but the emphasis on trying to preserve life is tantamount and enormous. Even if a person is only partially aware, there is some sense of the meaning, of a meaningful existence for a person, even though there may not be hope for a return to complete health. If there is, however, consciousness, awareness of other people, a feeling of a presence of others, then that is important to preserve, whether or not a person is in the process of dying. Of course, the decisions and the family gatherings and the disagreements and the intervention of the medical institutions have created a lot of problems. I can think of situations where people were kept in a vegetative state for a long, long period of time because the hospital had certain restrictions, the state had certain restrictions, or there were no instructions.

Nowadays, the living will has become very important. Too few people have one, although they should. It is something that Judaism certainly encourages because it makes decision-making so much easier for the family when the time come for such decisions to be made. The general principle is the sanctity of life on one hand, yet the compassion for the person who is suffering on the other, and thereby removing the impediments of death, and allowing a person a peaceful departure if there is no hope for return of health. A living will usually reflects that point of view.

Dr. Khan: Let me make a comment here. Professor Badawi mentioned that in Saudi Arabia the official position is that if three qualified and licensed physicians, agree that the person has reached the end of life, and there is no hope, they can sign a DNR order in the hospital. That is practiced all over. However, there are still some differences of opinion on that.

Case Study 3: Are there religious guidelines regarding sharing of “bad news” with patients and families?

Dr. Khan: The third presentation is a very common scenario, particularly in different cultural settings. A case from Saudi Arabia illustrates this.

Mr. A is a 70-year-old man referred to the university hospital for cardiac catheterization. He has history of right nephrectomy three months earlier for renal cell carcinoma. Cardiac catheterization revealed three-vessel disease not amenable for angioplasty. The patient was referred for bypass surgery; however, regular chest radiography revealed a lung nodule. Work-up of the lung nodule was positive for metastatic disease. The patient’s son is a family physician who reported that his father does not know about the kidney cancer and requested that he not be informed.

An oncologist was consulted and refused to give chemotherapy without informing the patient who was mentally competent.

Dr. Smith: I am going to start with the Protestant viewpoint, which historically has been dominant in America and arguably influenced the Catholicism that emerged from Vatican II. One Protestant idea that emerged early in the Reformation was quite revolutionary in its time: the idea of the priesthood of all believers, that you do not need a priest and a hierarchy to mediate between you and God; that every believer has direct access to God through prayer. In fact, God expects that kind of communion and wants it with every person. No human being can mediate that relationship with God other than Jesus Christ, who as the Son of God participates in God’s own being.

This empowering Protestant emphasis on the individual in direct communication with God, I believe, has a great deal to do with the emphasis on respecting individual autonomy in the United States, as well as on the principle of informed consent, even though it took centuries for these ideas to be fully defined and accepted. In some sense, every individual has the “right to know.” In the 16th century, the Reformers said that every person — even the most common — can read the Bible in his or her own language. Of course, the recent invention of the printing press facilitated this encouragement to “read for yourselves,” allowing Protestantism to spread like wildfire in Europe and empowering people to read the scriptures for themselves and make their own decisions. Now this emphasis on individual knowledge and decisions may have a downside as well, which is to throw out a lot of useful tradition and to weaken old bonds of family and society and culture, which are important in nurturing and comforting the individual.

With respect to the case Dr. Khan presented, I think we would all recognize that most individuals do not actually learn and make decisions as atomized selves, unaffected by the influences of loved ones or extended family or of a tradition or culture that helps one to interpret life; nor do they aspire to such a marked individualism. The law may suggest that, for a competent person, the only informed consent that matters is that obtained from the individual, without reference to family. However, from an ethical standpoint, part of our duty to respect is to determine what the father’s wishes are for receiving information and for making decisions. The father may entirely agree that medical issues should be mediated through the son. Some people do want their relatives to decide for them.

However, lest we fall into stereotypic thinking about cultures, let me tell you about an experience I had with a Chinese woman, a 50-year-old physician who had emigrated from China and who was dying of metastatic colon cancer, when I was asked to see her to address the palliative care option. She spoke only Mandarin. One of the many friends around the bedside told me that the patient’s main wish was to have her son come from China to see her. Since he could not get a visa, the friend said, she wanted to fly back to China. I asked the social worker to check out this option. The next day, I found her alone and spoke to her over a translator phone. When I said to her, “Doctor, I understand you want to get back to China to be with your son," she erupted almost violently: "I do not want to go to China. I want to stay here. I want to be cured." I learned an important lesson, as well as the value of translator phones.

Along similar lines that may puncture cultural stereotypes, a group of researchers in Kuala Lumpur, Malaysia, interviewed 15 patients about attitudes toward advance directives. Half were Muslims; the rest were Buddhists, Hindu and Christians (typical of the heterogeneity of Malaysian society). All but one of the subjects said that they would want their doctor to fully inform them about an illness. Two essentially responded: "I am not even going to designate a family member as proxy because I cannot trust them; they will tell the doctors to keep me alive forever." Only one subject agreed that "the Malay way" was to go through your family; but she wanted to fill out an advance directive as soon as possible so family members at least would know what she wanted.[5]

Conversely, a recent article in the *New York Times* told the story of a palliative care specialist at a New York hospital who was in her 40s and had been wrestling with breast cancer for many years. Even though she understood and practiced palliative care, she was young, had been managing her disease for a long time, and wanted to live. She decided, "I do not want to know the details" and handed all decision-making over to her husband, after giving him some guidelines that focused on fighting to stay alive. As a result, she received aggressive care until the very end, with a change to a palliative approach only in the last days of life. Hers was a personal decision, not one based on religious or cultural influence. Her story — on the surface, a seeming paradox — tells us that respecting autonomy means respecting how the patient wants information communicated. It also underlines the fact that "you can not tell a book by its cover," that we must be careful not to stereotype people by profession or culture or religion or other group traits.

This anecdote illustrates that it is very important always to ask the competent individual patient, "Do you want to be fully informed and make your own decisions, or do you want me to go through a family member?" Returning to the case Dr. Khan described — and assuming that chemotherapy treatment is not likely to succeed — I would ask: if the gentleman does not know that he has metastatic renal cell cancer, how does he face his own death, how does he prepare for death? Preparation for death would seem to be important in all three of the Abrahamic religions represented here today.

And, of course, you do not have to be religious to have remorse. We may have sins for which restitution provides the best assurance of a peaceful death. Twenty years ago, I admitted a man in his 40s who came to the hospital with widely metastatic, end-stage melanoma. The nurse perceived that he had great spiritual distress and — although I do not believe the man was actively religiously observant — she called in the hospital chaplain, who discovered that the man had abandoned his wife and family 15 years before and was alone. The chaplain contacted the patient's children and brought them to the bedside. There the chaplain facilitated a profound reconciliation based on atonement and forgiveness, and the patient was able to die peacefully, in a state of grace.

Thus, I believe that respect for autonomy has a strong spiritual (and specifically Christian) foundation. I would assert that every person needs to be given the opportunity to hear the diagnosis and prognosis and to decide about the goals and proposed interventions in future medical care. Respect for autonomy also means that if the patient wants information to be mediated through a trusted surrogate, then we must abide by that decision. If, after being asked, the patient in Dr. Khan's story says "No, I want my son to mediate all information and to make all the decisions, and I do not want to know anything that he chooses not to tell me," then that should settle the issue. Henceforth, the physician should go through the son, unless the patient changes his mind.

Rabbi Davidson: I think Judaism takes a bit different point of view with regards to that, not entirely, because the bottom line is human judgment, judgment of the family, and judgment of the physicians. It is very hard to have an absolute iron-clad position that is going to be right all the time because there is so much that is uncertain and gray in all that we have been talking about. Basically, in Judaism there is an interesting tradition about telling the bare truth. An example that is often referred to is in the story of Abraham and Sarah, in which God, says to Sarah that she is going to give birth to a son, and she laughs and says, "Are you kidding, my husband is 90-100 years old, how am I going to have a son?" And then, when God goes to Abraham, and tells him that Sarah is going to have a son, God says to Abraham, "Sarah was surprised because she said how I can give birth being as old as I am?" God says, "Well, nothing is too wonderful for God." God did not tell the truth to Abraham. He did not tell Abraham what Sarah said because he felt that there should be, as we say in Hebrew, *shalom bayit*, peace in the house.

There is a principle that says there are times when you do not have to say everything that you know. A very clear statement in the Talmud says that if somebody is gravely ill and bad news could put them into a worse state they should not be told if someone in their family dies. You do not tell them, because you want to preserve their life. That is not to say that Judaism does not honor the truth, because it regards truth as one of the most essential ethical principles and points out that the Hebrew word for truth, "*emet*," contains the first, middle, and last letters of the alphabet; truth is all consuming. But from the point of view of compassion, from the point of view of the human element, one does not have to reveal the bare truth. So, if it is deemed wise that a person does not need to know everything, that judgment can be made. If you are going to help prepare a patient for death, think about what would you like to say, offer a prayer or express feelings that you want communicated in a less frightening way. This way preserves a sense of peace in the heart of the patient.

Dr. Badawi: First, I believe that in this issue, the question of patient autonomy is also very relevant. My understanding as a layman is that chemotherapy is quite an intrusive medical intervention. It is up to the patient concerned to determine whether to go through that and if it is worth trying. Second, I was very interested in Dr. Khan's remark that this is a case from Saudi Arabia. This underlines the need to distinguish between diverse Muslim cultures and normative Islam. In reality, there are a lot of un-Islamic Muslim cultures. As a person who came from Egypt long time ago, I noted that in some of the Arab and Muslim cultures, they would not even dare speak the word "cancer," as they consider mere utterance to be inappropriate if not devastating. Often time the patient is not even told of the cancer diagnosis. These cultural practices are not based, to my knowledge, on Islamic teachings as derived from its primary sources. Why should one hide the information from the patient who is most concerned about making decisions? Islam teaches its adherents to be forthright and truthful. The Qur'an is quite clear when stating that God created death and life.

A third point is that there is an important advantage of the patient knowing that his or her life is limited and that there is no known cure available. Such forthrightness is predicated on a core Muslim belief about the worldly life, the hereafter, resurrection, punishment and reward, and eternal life, hopefully in paradise. To the believer, this is a matter of reality, not speculation, imagination, myth, or theory. Against that background, a practicing Muslim is likely to be less fearful of death, at least the devastating fear resulting from the absence of any hope of future perfect life of felicity with greater closeness to God. Death is seen as no more than a transition from one level of existence to another. This belief is most commonly shared with the Christian faith. Furthermore, such belief serves as a spiritual and psychological preparation for death, which is seen as an inevitable normal process anyway. It is also helpful for the dying person to seek forgiveness of other people, pay debts to them, if any, and to attend to other worldly affairs such as making a will (which may include advance directive).

Case Study 4: How much and how long do we care for hopelessly ill patients and should cost be a factor in decision-making? The Case of Terri Schiavo.

Dr. Faroque Khan:

- Feb. 25, 1990: 26-year-old Terri Schiavo suffers cardiac arrest and she lapses into a PVS for 15 years. The cause of her sudden cardiac arrest was not determined. She died of dehydration on March 31, 2005, nearly two weeks after her feeding tube was removed in accord with a court order.
- Her husband, Michael Schiavo, had long sought to have the tube taken out, arguing that she would not have wanted to be maintained in a vegetative state, but her parents fought to keep her alive. Members of Congress, the Florida Legislature, and Florida Governor Jeb Bush tried to intervene to keep Ms. Schiavo's feeding tube in place.
- After many appeals and judgments in November 2002, a judge again ordered Terri Schiavo's feeding tube removed. The Schindlers, Terri's parents, appealed again.

- September 2003: With appeals running out, the Schindlers ask a federal court to intervene. Governor Bush files a brief in the case supporting the Schindlers.
- October 10, 2003: The federal court judge says he has no jurisdiction in the Florida case.
- October 15, 2003: Doctors remove the feeding tube.
- October 21, 2003: Governor Bush successfully pushes for an emergency act of the Florida state Legislature to restore the feeding tube. The law becomes known as "Terri's Law." A lawsuit challenging its constitutionality is immediately filed.
- September 23, 2004: The Florida Supreme Court strikes down Terri's Law.
- January 24, 2005: The U.S. Supreme Court refuses to hear arguments for Terri's Law.
- February 23, 2005: A hearing is scheduled; the Schindlers ask for more time to file appeals, which would address whether new therapies will help their daughter and whether their daughter's religious beliefs prohibit withholding nutrition.
- March 18, 2005: Feeding tube is removed and 13 days later, on March 31, 2005, Terri Schiavo dies.

Several questions come up with this. Is PVS a hopeless situation? Is the feeding in this case normal or extraordinary care? What about the cost of care? This young woman received total care for 15 years. I guess the cost must have been more than $1 million. Should the cost of care ever enter the equation? Who is going to pay for this? Is it the individual's or society's responsibility, or both? Which takes preference based on religious practice? Very few people talk about the economics of health care, and I thought it would be a good opportunity to have a discussion here and see where it goes as far as health care cost implications. In the United States, healthcare cost is a major issue, and it is now becoming an issue all over the world. The bottom line is that expensive technology has proliferated. Who is going to say enough is enough? What is the role of the physician? What is the role of the religion?

Dr. Smith: The issue of whether to insert or to withdraw a gastrostomy tube often comes up in palliative care. The usual approach is for a gastroenterologist to pass a flexible endoscope from the mouth into the stomach. A hole is then punctured through the skin into the stomach from outside, and the feeding tube is inserted through the hole and anchored within the stomach. The entire procedure is called "percutaneous endoscopic gastrostomy," and is commonly known by the acronym PEG. Feeding can then be directed straight into the stomach in liquid form, usually up to 60 milliliters (or about ¼ cup) every hour. If the stomach is not emptying well, the liquid can back up in the stomach, leading to one of the serious complications of tube feeding: aspiration of the food that results in pneumonia. Usually, the tube is inserted to avoid swallowing problems, which may lead to food going into the lungs; yet even though the PEG is intended to avoid aspiration, many patients still aspirate with PEG feeding.

Of course, the procedure for inserting the PEG can also have complications (a 20% rate is reported at my hospital). Many are mild, but some complications are very serious, such as having the tube go into the colon, or development of an abdominal wall infection that is difficult to treat.

Only a few conditions exist in which there is evidence that feeding tubes are beneficial, such as strokes in previously healthy people who are likely to regain swallowing function. In individuals who have received radiation for neck cancers and are unable to eat because of inflammation and pain, the PEG tube can provide a nutritional "bridge" until they are able to eat again. Individuals with amyotrophic lateral sclerosis (ALS) have been shown to benefit from tube feeding when they can no longer swallow. The last indicated condition is persistent vegetative state, in which tube feeding is the only way the patient can survive, if long-term survival was the patient's wish. Tube feeding kept both Karen Ann Quinlan and Terri Schiavo alive for years, until the individuals died from a complication of being chronically bedbound.

Ms. Schiavo did unusually well physically until she died as a result of withdrawal of PEG tube feeding. Her husband ensured that she received excellent care for years, even taking her to specialists in California for experimental treatment. Ultimately, the courts were persuaded that long-term survival by mechanical means — in a state of unconsciousness — was against Terri's previously expressed wishes.

Let me address the issue of keeping permanently unconscious patients alive with modern technology and its implications for health-care costs, distributive justice, and other ethical concerns. One of the central convictions of Christian faith is that death need not be feared. In a sense, persistent vegetative state is a way of dying very slowly; it is rare for individuals with PVS to live as long as Ms. Schiavo did, and most will likely experience more medical complications. They may not feel pain, but the situation certainly is burdensome for the family. As a result of the Terri Schiavo case, the Vatican (under John Paul II, who died shortly after Terri Schiavo) announced that providing artificial nutrition and hydration (ANH) is not a medical act, and that it is really ordinary care in today's society. However, this is a change from the previous Roman Catholic position, which viewed ANH as an extraordinary, nonobligatory intervention. Many Catholic ethicists still take issue with the Vatican view (which has not been accorded the status of infallible dogma), arguing that to make ANH obligatory violates traditional Catholic teaching about the proportionality of means to ends. Certainly most mainstream Protestants do not agree; evangelical Protestants have been somewhat split on this issue, despite the prominence of some who were in the forefront of holding up Terri Schiavo as an emblem of the pro-life cause.

Terri Schiavo's long survival with ANH seems to me to highlight the issue of distributive justice, which America has yet to come to terms with because of the resistance to the notion of "rationing." Of course, the truth is that we already ration health care based on what job you have, how much money you have, where you live, whether you are poor enough to be eligible for Medicaid, or old enough to qualify for Medicare. We have rationed until now by keeping 44-50 million people uninsured. At best, the new "Affordable Care Act" may cut the number of uninsured down to about 14 million. As Dr. Khan said, one-third of Medicare dollars is spent in the last year or two of life, all of this occurring in a country with huge national debt and annual deficits, and falling economic and educational standing in the world. We have to come to terms with the fact that we are not going to be able, as a society, to pay for every health good for everybody. Sooner or later we will have to entertain a more formal kind of rationing, which will leave some services uncovered, at least by taxpayers, and probably by insurers. Some of these decisions will be very tough to make.

Social justice is a very important component in the Christian – and especially the Catholic – tradition. I believe that our duty to social justice requires that we examine the extent to which the cost of using modern technology to keep permanently comatose people alive consumes resources that could extend the lives of conscious people who are excluded by American insurance systems. There are about 15,000 people with persistent vegetative state in the United States. It costs at least $60,000 a year to keep someone alive in a persistent vegetative state. In addition, we have not mentioned the even greater numbers of very old people receiving ANH because of advanced dementia, a condition in which there is no evidence that feeding tubes improve quantity or quality of life.

To summarize, as a Christian, I am challenged to believe that death is not "the end," and I am called to join with others in advocating for greater justice in the way my country distributes the scarce goods of health care. I do not have an issue with rationing some forms of health care – especially those which seem to have little utility as life end approaches – if such rationing is rational, fair to individuals, and just towards "the least of these, our brothers and sisters."

Dr. Badawi: This is perhaps the toughest case. You are keeping the best to the end, right? I would like to make four comments. First, if we are talking about costs in absolute and unqualified terms, it is unacceptable because it is like putting a price tag on human life and saving one life is like saving all of humanity. We are dealing with the main determinant of medical intervention. The second comment relates to the issue of quality of life, which is undefined and quite tacky. Who determines what quality of life is and what are its boundaries? I am not getting into that, but to me there is basically one issue of concern: what will happen if the patient is left without medical intervention? Can we consider a case like Terri Schaivo's as a practical example of the beginning of the process of death? If so, and no intervention takes place, the process will just take its course. In that case, would intervention constitute an impediment and an interruption of that process of death that has already began? Look from the other end, would that intervention, if opted for, lead to cure? Could it lead even to "coming back to life"?

What would happen if and when intervention is withdrawn? If it is determined that only part of the brain is "dead" should that affect the intervention option? I know that there are some issues that are still debatable and need further research. If it is decided that intervention is futile, maybe then we can look into the matter of cost and other legitimate considerations. In his book *Fatāwā Mu`āṣira*, Shaykh al-Qaraḍāwī suggests that consideration should be given to the suffering of the family, the major interruption of their schedule and life due to their presence in the hospital for an extended period.[6] Second, Dr. Khan spoke about the immense financial cost of keeping a person in a vegetative state, sometimes for many years. Given the limited resources available and the need for expensive life-support equipment, especially for patients who stand a good chance of recovery, the issue boils down to distributive justice. Would it be wise to tie up limited and needed resources when their use is futile, when there is no viability? It should be reiterated again that such questions are tacky and are related to other controversial questions such as: Who decides what? What is the role of the family of the terminally ill patient? What are the legal considerations? No attempt was made to delve into these questions. I tried to focus on a few pertinent issues from an Islamic perspective.

Rabbi Davidson: I have just a brief response, but first I want to just add one comment to what I had said before about telling the patient the truth. I did not mean to imply that the patient does not have the right to know, what I was trying to say was that if it is clear to the family and the physicians that a certain amount of information is going to be harmful and probably unproductive to share, and if the physician and the family know that the patient feels that way, and there is a sensitivity to that, then it is permissible to withhold the bare truth. Because certainly every individual has a right to know, if they want to know, and if it is appropriate that they know, and if there is a possibility that they will take action or accept a certain kind of treatment that would make a difference, then clearly that should be revealed. However, there is permission to be less than 100% truthful if sound judgment makes it seem that it is appropriate.

With regard to the issue of the expense of the Terri Schaivo situation and like cases, to keep someone alive when life is not viable or meaningful and it is just a response to mechanical apparatus or to feeding and not a sense of being alive whatsoever, then Judaism believes treatment should be ceased, and impediments to allowing death should be removed.

I love what was said about the wonderful line that both Islam and Judaism share in their sacred texts, to save one life is to save the world. If there is the possibility of viability of life, if life is meaningful to a person, even if it is not in the fullest of the health that we cherish, we have to as a society do the best that we can to preserve that life and to use whatever methods and means we have to do that.

The issue of proportionality, which I think is a good word, has to be applied. If there are a limited number of uses, let us say for a dialysis machine or some other medical device, then I think the decision, painful though it may be, probably has to be in terms of who will benefit the most from a particular procedure that simply cannot for one reason or another, financial or otherwise, be shared as broadly as one might wish it to be. I think our society does have to remain committed to that core issue that we have all shared, the sanctity of life as much as it is possible to do so. If we begin to put a price tag on what that means, the ultimate consequences could be very painful and really bring us into grave moral issues.

Questions from the Audience

Dr. Khan: *Let me start by asking the first question from my mentor Dr. Badawi. We talked about certainty, but we are taught that humans can never be 100% sure; only God knows everything. So as a physician, if I have a patient in vegetative state in front of me, how can I make that call that this patient is going to go this direction and not going to make a miraculous recovery?*

Dr. Badawi: This is a tough issue because there are limited areas of decision-making where you have absolute and utter certainty. In Islamic jurisprudence, there is a rule known as *ghalabat al-ẓann* meaning that, short of 100% certainty, there are cases where there is near certainty or high likelihood of one among several possible outcomes. Some jurists submit that, if you require full certainty before making a decision, you will be paralyzed and unable to make any decision.

The issue here is whether, from medical experience, the chance of a person in persistent vegetative state for many years may come back to normal life is one in a million then there is another rule that might help in decision-making. It is called *al-shādhdh lā ḥukma lahu*, which means that if a possibility or scenario is extremely rare and unlikely, there could be no systematic rule to address it. I may add here that when applying any of these two rules in a matter of life and death, as Rabbi Davidson, Dr. Smith, and myself indicated, utmost respect of the human sanctity of life must be shown. It is not like prescribing a medication or recommending a specific medical procedure knowing that there are some harmful side effects and even rare fatal results. The issue here is whether the potential benefit outweighs the potential harm. The matter really is and ultimately predicated on whether it is really impossible or near impossible that a person comes back to life in a case like the present one. That makes me move the ball to your court as physicians and experts.

Dr. Smith: When evaluating severely impaired consciousness, one has to distinguish between PVS and minimally conscious state (MCS). Patients in the latter state retain some higher function; they may hear words and may experience pain and suffering. A few individuals with MCS may return to consciousness, sometimes many years later. (The hypnotic drug Ambien has wakened a few people with MCS.) However, the diagnosis of PVS cannot be made for at least six months after onset of the condition. After one year of coma, the chances are almost zero that a person in PVS will return to consciousness.

Physicians in palliative care are always acutely aware of the uncertainty of prognosticating. We cannot deal with probabilities with statistical or legalistic precision. Palliative and bioethics consultants know they must always see and talk to the person or his family, or both, in order to make or facilitate appropriate decision-making. As an example, at North Shore University Hospital, we take care of many strictly observant Orthodox Jews — many from Iran — who believe that if there is any chance a person can survive for a time with intubation, even if the extension of life is not long, then they should be maintained on a ventilator. During a telephone conversation regarding a patient, a rabbi may ask if there is a 10% chance of survival. Because I usually cannot exclude a "10% chance," I honestly say so; and the answer is "Then you have to use the ventilator." However, if I have the rabbi come to the bedside and actually see the patient, he may recognize the dying process, and say, "This person is dying. You should not intubate this person." This illustrates the importance of having the religious adviser see the patient, to observe the patient's condition directly. Perhaps Rabbi Davidson can speak to the concept of *goses* in Judaism

Rabbi Davidson: *Goses* is a person who is dying. The only thing I can add to this is that there is an official rabbinic view that if a person is dying and there is one or another treatment that has a risk to it, but that might help, it is permitted to try that, even if it might end the life a bit more quickly. If the person is really on his or her very last days, one can take that kind of risk according to Jewish Law.

Dr. Packer: *My question relates to when talking about the end of life and some of the challenges we have. I think one of the recent challenges is organ donation after cardiac death. When we have a brain-dead person, there is proportionality because many people can live with that person's donated organs.*

I also have a comment. Persistent vegetative state now is being thrown into a research area that is creating ethical difficulties, and that is deep brain stimulation. Now you can take a 22-year-old motor vehicle accident victim, a perfectly healthy kid before, and now is six months out. Several neurosurgeons around the world are now taking electrodes and putting them in the middle of the brain to reverse the mental status of that patient so he goes from persistent vegetative state to a minimally conscious state. We just have to understand that the challenges that are being presented to us technologically are mind boggling and difficult to analyze. I would like to get to your opinions about cardiac death as a definition.

Dr. Smith: In the past, organ harvesting for transplant generally was done on people who were declared brain dead. Legally the person is considered dead and can be taken to an operating room on life support and the organs harvested there for transplantation. Usually, in that situation, you are trying to maintain optimal function for the organs until the transplant. Remember, a single person's donation may benefit many people, with kidneys, lungs, liver, heart, pancreas, etc. Donation after cardiac death (DCD) is probably a little more controversial. An example is a 22-year-old with a brain hemorrhage who does not respond to neurosurgical intervention and will surely die. However, he is not brain dead and could be kept alive for quite a while, if not indefinitely, with mechanical ventilation and blood pressure support and other measures. The Organ Donor Network would be called and would discuss the option of organ donation with the family. If the family agrees, and it is believed that death will rapidly follow removal of respiratory support, the patient would be taken to the operating room (after appropriate family good-byes), and the ventilator would be withdrawn. When the heart monitor shows the occurrence of cardiac arrest, after a period of about two minutes, a surgical team can come in and harvest organs. This is a summary of DCD.

Because in DCD, the patient is not yet brain-dead, and withdrawal of the ventilator allows cardiac death, there may be concern about a potential slippery slope that could lead to inappropriate hastening of death to support a transplant program. Again, from a Christian perspective, I do not see a problem with DCD if the best medical expertise has been applied and in good faith concludes that life-prolonging treatment would not be helpful to this person's survival, but would only add to the intolerable burden of a family that feels obliged to prolong the dying process as long as technology allows.

Rabbi Davidson: Yes, I think that would be reflected, at least from a liberal Jewish point of view without much question, assuming the family and living will and all of the other aspects of this are there.

Dr. Badawi: Let me test my assumptions first because one of the important aspects of any religious opinion is to understand the issue at hand. My humble understanding is that brain death does not preclude cardiac death. It is simply a finer definition because you could still have the heart working through life support equipment, even though the brain is dead? Is that correct first? Based on that and according to a juridical, the answer is yes, because the person is deemed dead, whether through cardiac death or brain death, keeping in mind all the intricacies we discussed earlier. If he is deemed dead and he made a will to donate organs, then, yes, you can retrieve the donated organs. If it is necessary to keep the life support equipment for a limited time after death so that the retrieved organs can be usable, then it is permissible to do so.

Dr. Smith: May I ask you a question, Dr. Badawi? In the situation I described, although there may be very severe brain damage that precludes recovery, the accepted definition of "whole brain death" has not been met. The person may take an occasional breath and certain reflexes may still be there, but the understanding is that he has permanent respiratory failure and will not recover consciousness or survive for long even with maximal life support. By withdrawing the ventilator, we are withdrawing the technology that is keeping him alive. The heart will soon stop because of lack of oxygen, and this in turn will lead to rapid brain death. So the sequence in DCD is (1) respiratory arrest, (2) cardiac arrest, and (3) lastly whole brain death.

Dr. Badawi: I was careful not to encroach on areas beyond my competence. I simply said that DCD is permissible if the person is "deemed dead." It is up to the experts to determine whether there is any chance of that person coming to life again or whether any spontaneous breathing or other movements are definitive signs of "life" or any hope of returning to life.

Cheryl Mwaria, PhD: *I am the chair of the Anthropology Department here at Hofstra and I am a medical anthropologist. I would like to thank our panel of religious scholars for a very informative and thought-provoking presentation. My question to you has to do with cost again, and of the mounting cost, and its relationship to physician-assisted suicide.*

In 1939, Hitler established the Nazi Tiergarten Euthanasia (T4) Program, and he did so at the behest of a German Christian couple who were elderly and very concerned about what would happen with their adult son who was profoundly mentally disabled. Now, in response to that, the T4 euthanasia program was established "to provide a good death," and eliminate "useless eaters" in order to conserve food, hospital facilities, doctors and nurses for the more important use of the German armed forces. There were safeguards in the form of a panel of physicians, but very quickly that program turned into a program based on cost. Do any of you have fears that that kind of a program could be established here in the United States, now that cost is becoming such an issue?

Dr. Smith: Well, I certainly have the fear about a potential slippery slope, and I think that we all have to be vigilant. Even if I am not of the same mind as an Orthodox Jewish scholar or an evangelical Christian theologian on this issue (and my own living will states that if a catastrophe leaves me with severe, permanent impairment of consciousness, I do not want to be kept alive indefinitely with either mechanical ventilation or a feeding tube. or both), I do think that we need traditionalists to help us pay attention to this kind of risk and to watch out for the slippery slopes.

I am less afraid of Nazi-type eugenics obtaining a foothold in the United States, in part because traditional religion has such a strong voice in our public square. I believe that most of the world's great historic religious traditions condemn euthanasia. Interestingly, in their latest edition of *Principles of Biomedical Ethics*, Beauchamp and Childress note that "some slippery slope arguments should be taken with the utmost seriousness."[2] They describe the worries that the legalization of physician-assisted suicide (PAS) in Oregon would be followed by increasing euthanasia — often for the kind of inappropriate reasons that seemed to accompany Jack Kevorkian's practices — as well as a deterioration in the quality of palliative care. They also observe that "none of the abuses some predicted have materialized in Oregon." The data show that the number of patients availing themselves of PAS has been very limited, with the numbers remaining the same at about 60 from year to year, and representing the better educated and medically well-served, rather than poor, disabled, or minority individuals who might be more vulnerable. Beauchamp and Childress suggest we must also look at data, value descriptive ethics and look at actual outcomes.

Rabbi Davidson: With regard to physician-assisted suicide, the Jewish tradition is opposed to it. It is, far from what I had spoken of before, removing the impediments to a peaceful demise. The notion of taking life is an anathema to Jewish thinking, although I am sure there are Jews and rabbis who might be able to go along with it in certain circumstances. As a position of the Jewish faith, we would be in opposition to it. Every effort should be made to give patients comfort, and if possible, cure, but not to take their lives.

Dr. Badawi: I concur with my respected colleagues, and it goes back to the statement made earlier that active euthanasia is totally forbidden in Islam. Remember also the remark made about the quality of life, for example, where do you stop? Down syndrome? See, it opens a big can of worms, but I wish to say that I am less concerned about this happening in America than in some Northern European countries. I suspect that for so many religious Jews, Christians, Muslims, and others, active euthanasia is unacceptable, and they are likely to continue to reject it. Maybe I am too optimistic, but I would like to be optimistic.

Dr. Chadda: *This question may not be related to the present discussion, but I am still going to ask you. Religiously, morally, and ethically, is it acceptable to discuss the cost of care of a patient in a vegetative state, while we are spending billions of dollars in wars killing people?*

Dr. Badawi: It is a very simple answer. I concur. If a fraction of the hundreds of billions of dollars used to destroy life and property is used for human welfare, we will have a much better world, and I hope we work towards that.

Dr. Smith: I agree with that sentiment. The problem with distributive justice in America is that cutting costs in one area of health care does not mean that that money goes to an appropriate health care for someone else who presently lacks access to care. For distributive justice to work, it is obvious that we need a social contract, a commitment to ration scarce and costly health resources rationally rather than irrationally. Until the American nation arrives at such an agreement, I do not think these issues can be resolved. The difficulty that our country seems to have in finding a way to assure a minimum standard of health care for every person seems the downside of our prevalent conservatism — a conservatism that I think is more cultural than religious because, in the Abrahamic religions at least, God is portrayed as calling those who "have" to be generous and just to those who are poor and "have not."

Rabbi Davidson: Well, just to echo, we have to reorder our priorities ultimately, and the huge amounts of money that go to destruction, to war, even if just a significant portion of that were turned toward human needs of all kinds, whether we are dealing with poverty or housing or education, but certainly medicine, I think we would be much better able to take care of our population.

Chaplain Angela Ceza: *I do pastoral care at the Unitarian Universalist congregation Shelter Rock in Manhasset. My chaplaincy training and my seminary education at Union have led me to be passionate about giving the "bad news." I think few families will agree to talk about death when someone is well, and there are a number of reasons that they do not do that. I think that some families interpret that to mean that the people who do not want to talk about it, should never be talked about the issues when they themselves are dying. In fact, what it often means is that in the family, different members are concerned that it* *is going to cause more infighting or that talking about it leads to it. You know we have heard that, if I talk about death, I am going to be closer to dying. That is one misinterpretation and obviously I want your comments on all or one of these. From my experience, I think the harshest words that families hear are "There is nothing we can do." When the doctor says there is nothing we can do, that is all the person hears, that is all the family hears, and they are devastated. Why cannot people, physicians, or any provider say the best treatment for you now is comfort care, and I will help you to do that. I believe the best treatment is comfort care. I cannot tell you how many people say to me, "I am waiting for my doctor." I do not know why they do not talk about hospice. And I say, "You cannot wait. You have to tell them you are interested." It is very frustrating.*

It is understandabe that physicians find this hard to do. That is why there are chaplains. That is why there are hospice care nurses in hospitals. The people are all there and available and would love to be with you and your families when you do that or soon after.

The third point is that the patient usually knows. When the chaplains speak alone with the patients and ask, "How do you think things are going? What do you think might happen in the next few months?" The patient always says, "Oh, I am ready to die. I am ready, but do not talk to my family about it because they will get very upset." That is the same thing the family is saying to the chaplain or the doctor. Everybody knows, but they are pretending. So no one does the end work that they would like to do, or a lot of times, as one of you were saying very well before, that the person could not go and do their last things. They could say goodbye and "I forgive you. Will you forgive me?" How fair is that? How truthful is that? How right is that? I just do not get it, I am so angry at people who do this because there are gentle ways and good ways of talking to people. You do not have to say, "Well, you have cancer, and you are dying." That is what people hear. The complaints I get are: "I cannot believe that someone said that to my mother, so I am never going to tell my father what is going on with him." We are making the problem worse instead of better. I would appreciate whatever comments you have on that. How can you help us?

Dr. Badawi: Whatever differences the panelists might have had about the extent of disclosure, I do not think that any of us is suggesting that the manner of communicating this information should be in a blunt or offensive way. I fully support your view that instead of putting things negatively, such a "we cannot do anything," we say: "We have tried all therapies that we are aware of, will continue to see if we can do more." Maybe at that stage to be more realistic, it would be a time for prayer. So, gentleness in conveying the information is a must.

Dr. Smith: As someone who has practiced palliative care in recent years, I have to keep reminding doctors to stop using a common phrase to describe the transition to a palliative, end-of-life approach: namely, the statement, "We and the family have agreed to withdraw care." In palliative medicine, we may withdraw a ventilator, but we never withdraw "care." Since withdrawal of a ventilator can lead to shortness of breath and distress, it is incumbent on the palliativist to intervene with aggressive, expert pharmacological treatment to prevent suffering. It is not the quantity or quality of care that has changed; but the type of care changes because there is a different goal: ensuring a dignified and comfortable death, rather than prolonging survival. Palliative providers are aware that cure or remission is no longer possible. They are just as confident that they can provide excellent "care," and that there may still be room for healing, which may be emotional or spiritual in nature.

Aasim Padela, MD: *I am at the University of Michigan. I am a clinician and a researcher and I just have a comment and a question. As a clinician, sometimes you find patients who have different views. For example, I know of a case where there was an end-of-life issue, and the physician and the patient were at an impasse. The physician brought forth a document from one of the religious councils, and said this is what the scholars say about this scenario, brain death. The family of the patient would not accept that statement, saying there are other opinions and that does not represent tradition. To a certain extent, I think that some of the panelists sort of presented their traditions as monolithic, and so I wanted you to comment on that, because as a clinician it becomes a problem if we take home the message: this is what our tradition says. To that extent, Professor Badawi, I would like to push you a little bit and ask a question. You said that Islam accepts brain death. However, when death occurs in Islamic law to my understanding, there are many rights that ensue. So the waiting period for the widow starts. You have to start the inheritance distribution and various other things. In the classic manuals, if there was a question about whether someone is dead, Imam Nawawi of the Shafi school says just wait until the body decays. The question becomes: do* *all these councils that you refer to state that brain death is legal death, therefore, everything can be done to distribute inheritances etc. Or is it unstable life, where certain things are done? You can withdraw care, but you cannot do other things, because you did not really mention that. If ontological death is brain death, then there are a lot of things that ensue. That is not my reading of the matter. Similarly, I work in Michigan where there is a huge community of Muslims numbering 250,000, of whom about 100,000 are Shias. They follow various Ayatollahs, and a community of them, about 50,000, do not accept brain death at all. Unlike New York state, we do not have a religious exemption to brain death in Michigan. So again, if you said Islam accepts it, there are quite a lot of issues with that statement. I just want you to talk again about what is death, ontologically, what is legal death for organ donation` and for various issues. Islam is not a monolithic tradition.*

Dr. Badawi: What I read about that, Dr. Padela, is that even if you pronounce the person brain dead, it is not exactly equivalent to the legal death, following which certain consequences begin, to be more precise. What I read is that you have to wait until breathing totally stops even though the person was already brain dead before that. Following legal death, the surviving wife of the deceased begins the observation of the period of mourning and the estate of the deceased can be divided after the payment of his or her debts. These are legal matters that should come after burial. As far as your question on the Shi`a community, they are free to follow their particular school of jurisprudence, and if they want to consult with doctors, they can find doctors who follow their particular school of law. There should be no compulsion in these matters. Even though a majority of Sunni scholars have given a verdict on any matter, that does not imply that the Shi`a community has to follow it. It is up to them. Similarly, with respect to the case that was presented earlier by Dr. Khan, if a physician says "I do not believe in brain death," such a physician is entitled to his or her beliefs, but he cannot be the decision-maker in that case. Nor should he or she be coerced to declare or sign that the person is dead. We have to respect the individuality of the physician also and their own beliefs. It is as if some doctors who do not believe in on-demand abortion can exclude themselves from that committee and let another committee or physician make that decision. Everybody should be accommodated according to their own beliefs.

Dr. Khan: Thank you panelists and the audience for a fascinating discussion. To summarize some take-home messages:

Case 1 — Brain Death: The three panelists emphasized the sanctity of life, and all faiths stress the importance of compassion towards the sick.

All were in agreement that in the absence of any hope for return to health and if there is suffering and pain, it is permitted to remove the impediments to death, for example mechanical ventilators, pressor support, artificial hydration and nutrition etc.

Case 2 — Advance Directives: All agreed that having advance directives is permissible and, in fact, is encouraged. Principles of proportionality of care and distributive justice were highlighted. There were some differences of opinion regarding "after life" in various faith traditions.

Case 3 — Breaking Bad News: The importance of patient autonomy in all three faith traditions was stressed, however, unique cultural and personal circumstances may require adjustments in how much information is given to the patient.

Case 4 — Terri Schiavo Case: Several key points were made in this discussion a) Nutrition and hydration, is it a medical act or routine care? b) Distributive justice and social justice, is it appropriate to consume precious health resources and extend life of permanently comatose people while resources are denied to conscious people who are excluded by the American insurance system. The concept of "rationing" of health care was briefly mentioned. c) Euthanasia is not permitted in any of the three Abrahamic traditions.

Concerns were expressed regarding the potential for getting on a "slippery slope" if health-care costs are used to determine type of care. The example of the German Teirgarten T4 Euthanasia program was cited.

Emphasis was placed on utilizing all the available resources — hospice, palliative care, chaplains — to ensure a transition to a type of care that ensures dignified and comforted death rather than prolonging survival. It would be greatly beneficial if clergy visited the bedside of dying patients so they get a better understanding of what health-care providers have to deal with in taking care of patients at end of life.

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