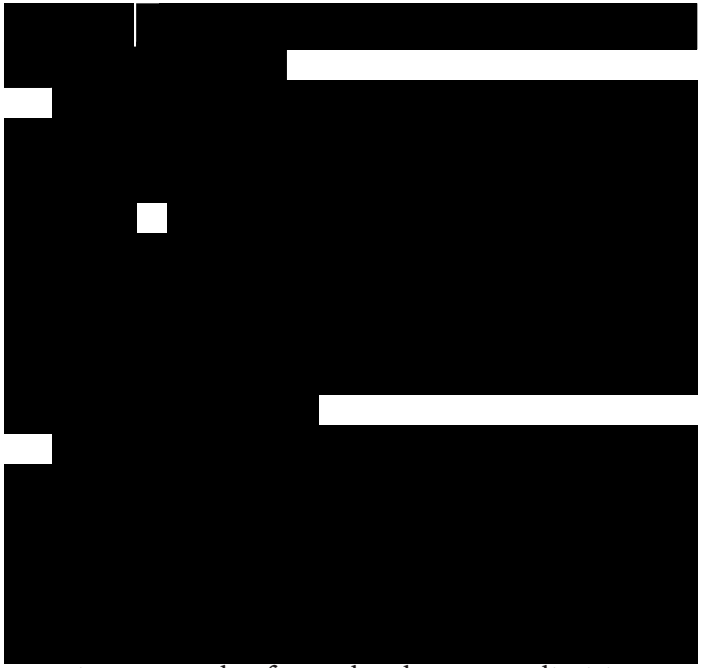
Panel Discussion

Muslim Perspectives on End-of-Life Issues

Moderator:
Daniel Martin Varisco, PhD
Professor of Anthropology
Hofstra University
Long Island, New York

Panelists:
Gamal Badawi, PhD
Professor Emeritus of Management and Religious Studies
St. Mary's University
Halifax, Nova Scotia, Canada

Shahid Athar, MD, FACP, FACE
Department of Endocrinology and Medicine
St. Vincent Hospital and
Indiana Unversity School of Medicine
Indianapolis, Indiana



Advance Directives and Living Wills for Muslims

Article DOI: http://dx.doi.org/10.5915/43-3-8478
Video DOI: http://dx.doi.org/10.5915/43-3-8478V

Shahid Athar, MD, FACP, FACE

I will start my talk with an actual case. JW, 74, the father of a Catholic physician, who is also an ethicist in a Catholic hospital, suffered a massive stroke that left him paralyzed with receptive and expressive aphasia. His advance directive stated that he did not want mechanical ventilation, nutrition, or hydration if he were to end up in a terminal state. He is now paralyzed and has expressive aphasia, but he is not terminal. He is somewhat conscious. His caregivers decided to insert a g-tube and start feeding. When he lapsed into a coma after 150 days, it was decided to stop the feeding and allow him to die peacefully at home under hospice care. Both his wishes were fulfilled, and all care was provided. The patient should have access to information, and his privacy and right to exercise control on self should be respected. When we are talking about rights, whose rights are they? What are the rights of man? What are the rights of the Creator? There is also the question of the ownership of the body. Do we have ownership of our bodies when we are dead or just while we are living? Can my wife after my death inherit my organs? Probably not. You may have right to donate an organ, but Islamically, do you have the right to put in your will that you should be cremated? No. Do Muslims have the right to seek Shariah rulings in end-of-life issues? Do we have a right to put Shariah rulings in our advance directives and living wills in terms of autopsy or other matters? Yes, we do. What is forbidden in life is desecration of the human body. Unnecessary mutilation of the body is not permitted while we are alive, and it is not permitted after death, unless it is required by law or a medical issue has to be solved. What is the underlying moral value? We should all be protected by the constitution and law. If you do not have a living will, and your body is still alive but in a vegetative state, your body becomes the property of the state, and the state sometimes decides what can be done. A physician who pulls the tube out on his own can be charged with murder. The Society for the Right to Die, a Boston organization, published a very nice book, *The Physician and the Hopelessly Ill Patient*.[1] That book outlines all the different states' laws. I will describe the Indiana law later. Informed consent is better described as the shared mutual consent that the physician participates in the informative process and patient partakes in an intelligent discussion, discussing with both the family and his care provider. Patients have the right to refuse treatment, but they have to understand the consequences of the refusal. Yes, I refuse to have my two legs amputated because of gangrene but the gangrene and infection and sepsis will proceed if I refuse to do that. I probably will die. Sometimes the problem is not with the patient, but it is with us, the physicians. We do not sit down and communicate with the patient. We instead have the nurse give the consent forms to the patient the night before or the early morning of the surgery. The patient is already drowsy and he signs it without understanding all the legal terminology. The physician needs to sit down and explain to the patient in a language that he can understand, and the patient has the right to make advance directives, and he has a right to a health-care representative.

So what is an advance directive? It is documented in advance of a critical illness, disability, or incapacity, that is before it happens. The directive states his or her wants, wishes about preferences about health care, including religious and moral values. Some individuals think that if they give an advance directive they will not be treated. Some individuals think that by appointing a health-care representative they are giving up control of their health-care decisions. I have appointed my son to be my health-care representative, and he will make all medical decisions for me. No, this is not true. You can still make these decisions as long as you are conscious. Some think it is only for elderly? No. Advance directives should also be for the young including the children who can understand. I propose that there should be a discussion on advance directives between each member of a Muslim family maybe once a month. Any expressed wishes should be recorded. Another misconception is that an advance directive is a permanent document, that it cannot be

Correspondence should be directed to

Shahid Athar, MD, FACP, FACE
sathar3624@aol.com

changed. That is not true. A person who has given do not resuscitate (DNR) order initially can change his or her mind later when circumstances change, for example, if an acute manageable emergency is superimposed on his or her chronic problem. Another misconception is that verbal wishes are not legal. They are legal and have to be implemented. If you express to your physician a wish, and the physician writes down in the chart that on such and such day the patient expressed to me that no tube should be put in his throat that should be enough. Another misconception is that physicians do not have to follow one' wishes because they are "gods;" they will do what they want to do. This is not true. Physicians have to follow but they need to know what are your wishes. That is why it is important that you express your wishes. In Indiana, advance directive law allows having a living will, a life-prolonging procedures limitations, saying such procedures that may be futile should not be done. For example, it may say that you do not want to be kept on ventilator for a long period of time; such as what happened to Terri Schaivo, who was kept on tube feeding for 15 years. Anything you want to put like this is usually implemented. The law permits the appointment of a health-care representative, of power of attorney, of a psychiatric advance directive because psychiatric patients are not mentally competent, therefore somebody else has to take care of them. The law also allows the person to indicate if he wants to be an organ donor and which organ(s) are allowed to be donated, because in Islam sex organs cannot be donated nor transplanted. Therefore, you need to be very clear in expressing your wishes; you need to know your values. Indiana law allows out-of-hospital DNR. Requirements to be able to have a living will include being an adult of sound mind. It should be voluntary, in writing, dated, signed, and witnessed. The law specifies who cannot be a witness to a living will: a parent, a spouse, the child, and someone who may be a beneficiary of the estate of the person. It must be a person who is not responsible for health-care expenses. The living will should have provisions, such as "my dying should not be artificially prolonged in case of incurable injury, disease or illness, or if my physician knows that my death will occur in a short period of time." "Use of life-prolonging procedures should not prolong the dying process." "I will be permitted to die naturally, that means at home and at peace." "That I am provided with appropriate pain control." It also permits reference to artificially supplied nutrition and hydration. To withhold nutrition and hydration in a person with persistent vegetative state may be inappropriate, but the patient has a right to enter yes or no to artificial feeding and hydration or he may state "Let my health-care representative decide on this issue." Hospitals are asking when you are admitted for any procedure to sign a living will if you do not have one. The cost of care increases for those who do not have a living will and are admitted to the hospital because their length of stay increases.[2]

A competent patient may refuse any medical treatment even if it is life-saving, so this is his right but he should understand the consequences. A health-care representative is an appointed individual who can make health-care decisions on behalf of another individual who cannot make medical decisions for himself because he lacks capacity. While you are competent you can override your health-care representative, but if you are unconscious, then that person will speak for you. The health-care representative acts only when the appointer lacks capacity. He can act in all matters of health care. He must act in the best interest of the patient, not his own interest, whether it is financial, legal or otherwise. He may delegate power to someone else for example if he has a relative who is a physician, he can share that responsibility with that person, but both must act in good faith.

The power of attorney is more of a legal term for someone who can be financially responsible to write checks on your behalf or take care of financial matters related to health care. Usually the power of attorney is given to a relative. My wife has a power of attorney for me, and I have power of attorney for her, but if God forbid both of us die at the same time, then my son has power of attorney for both of us. The person after that son is my attorney, who will also have some say. So it is a shared responsibility. The power of attorney can be executed only when you are conscious, must be in writing, must be notarized, and must be specific to what powers you want to give. When used to convey health-care power, the attorney in fact is referred to as health-care power. There are two types: financial and health-care power of attorney. There is a question about competency and capacity. Competence is a legal term. It is decid-

ed only by the court. On the other hand, capacity is decided by physicians. It indicates whether the patient is able to comprehend, to deliberate, to communicate.

I will now discuss the feeding tubes and their two issues: when to insert and when to withdraw. We insert a tube for hydration and nutrition after abdominal surgery if the patient is unable to eat or if the patient is comatose. If the coma is expected to be temporary there is no problem. If it does not seem to be a reversible coma, for example in a patient with respiratory failure or in a terminally ill patient, there will be a question of withholding the feeding tube. First, the physician has to see the need for the feeding tube and then whether in certain cases is it moral to withhold the insertion. The question is can a person with no capacity for awareness experience burden being on life support? Do we understand the his pain and suffering? Are we keeping the patient alive just for our own benefit because we would like to be with our loved ones longer? Is it for us, or for that person? That is why a decision has to be made, and it is best to have the opinion of three physicians. Those physicians should be competent physicians, preferably a neurologist, a pulmonologist, and a cardiologist or an anesthesiologist. A dermatologist or a cosmetic surgeon, although licensed physicians, should not be on that committee. It would be nice if you had a religious scholar available to give some guidelines.

What about family disagreement? What happens in practice is sometimes quite alarming. There was a case where there were three children, one living in town who has been taking care of the mother, and one living all the way in California, and the other in Hawaii. The sons who have not been living with the mother were the most vocal, urging that "everything needs to be done," probably because they had a guilt complex. What should be done if there is a family disagreement among the children? If there is no living will or power of attorney or a health-care provider documentation, the matter will have to go to the court, as in Terri Schaivo's case. One has to have family conferences in advance rather than waiting to the last moment to determine who will be speaking for the family and what the wishes of the patient are. A very important article by Silveira et al appeared in the April 1, 2010, issue of The New England Journal of Medicine. There were 3,746 subjects age 60 or older, and 42% of them needed decision-making. Out of these, 73% lacked decision-making capacity. Those who had durable power of attorney for health care were less likely to die in the hospital than those who did not (38.8% vs. 50.4%). Those who did not have living wills or durable power of attorney put the responsibility on the hospital, and the care was more prolonged and costlier. Everything that can be done has to be done. You call the consultant, the consultant has to do dialysis and this and that. Everything needs to be done. Those who had living wills were given less of "all possible care" (8.1% vs. 27%).[2] Another article in the Annals of Internal Medicine in August 2010 titled "Redefining the 'Planning' in Advance Care Planning: Preparing for End-of-Life Decision Making" addresses this subject.[3] IMANA recommends that all Muslims have a living will, advance directive, and proxy case manager to let the physicians know patients' wishes when they cannot give directions i.e. when they are in a state of coma. This is part of position paper published in 2005.[4] It had these components: respect of patients' autonomy to withhold or withdraw heroic procedures in a terminal state, to continue hydration, nutrition, and necessary medication, to appoint a case manager and to not have an autopsy unless required by law.

References

1. Society for the Right to Die. The physician and the hopelessly ill patient: legal, medical, and ethical guidelines. New York: Society for the Right to Die; 1985.

2. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. N Engl J Med. 2010;362:1211-8. http://dx.doi.org/10.1056/NEJMsa0907901

3. Sudore RL, Fried TR. Redefining the "planning" in advance care planning: preparing for end-of-life decision making. Ann Intern Med. 2010;153:256-61. PubMed PMID: 2935810

4. IMANA Ethics Committee. Islamic medical ethics: the IMANA perspective. J Islam Med Assoc. 2005:37:33-42. http://dx.doi.org/10.5915/37-1-5528