Religion and Physician Disclosure Play Key Role in Quality of Life at End of Life

'Art of Medicine at End of Life' Symposium

Religion & Physician Disclosure Play Key Role in Quality of Life at End of Life

By Brande Victorian

NEW YORK CITY—Religion and uncertainty regarding physician disclosure are two key factors that affect a cancer patient's quality of life at the end of life. So said speakers here at "The Art of Medicine at the End of Life," a symposium sponsored by the University of South Florida College of Medicine and the two-year-old Cunniff-Dixon Foundation, which has as its stated mission the enrichment of the physician-patient relationship at the end of life.

Susan Block, MD, Chief of the Division of Psychosocial Oncology and Palliative Care and Associate Professor of Medicine in the Department of Medical Oncology at Dana-Farber Cancer Institute, opened the symposium with preliminary analyses that she and lead researcher Holly Prigerson, MS, PhD, Director of Psycho-Oncology Research in the Division of Psychosocial Oncology and Palliative Care at Dana-Farber, compiled.

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Unnecessary physical and emotional suffering, disconnection, lack of preparation for death, and burdensome, ineffective, expensive care at the end of life, were factors found to affect patients' ability to have peace, Dr. Block said.

Citing SUPPORT, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, led by Joanne Lynn, MD, Director of the Washington Home Center for Palliative Care, which evaluated 4,301 hospitalized patients from 1990 to 1994, Dr. Block noted that half of patients die in the hospital with moderate to severe pain more than half of the time, and that almost half of the patients who die spend more than 10 days in the intensive care unit.

> *"70 percent of patients in the study in their last six months of life reported that there had been no discussion with their physicians about the end of life."*

That study involved having nurses meet with families, patients, physicians, and other members of the medical team in order to enhance communication, but these efforts had no effect on how patients died.

"You really need to focus on oncologists, and what they say, and how they say it, and when they say it, and how it affects the patient's emotional and cognitive acceptance [of their impending death], and how both those things will affect their use of palliative care services and their quality of life at the end of life," Dr. Prigerson said in a telephone interview after the symposium.

Whether physicians are having these discussions at all, though, is the primary issue to tackle, she said. A previous study by Dr. Prigerson found that 70% of patients in their last six months of life reported that there had been no discussion about the end of life.

One of the main reasons for this, she said, is the belief that having this discussion will dash patients' hope. However she is currently reviewing data that show that this discussion does not affect patients' mental health, and in fact increases the chance that they will die in hospice.

"If there's no psychological harm and there are benefits towards the quality of life at the end of life, then it would suggest to an oncologist that it's okay to have these discussions," she said.

Arthur Caplan, PhD, Professor of Bioethics at the Center for Bioethics at the University of Pennsylvania, who also spoke at the symposium, agrees with the need for oncologists to have these discussions: "If you just leave it to the patient to pick options, the patients are often too guilty, too emotionally upset, or too ignorant of what they're being asked to make choices about," he said. "They want help, and physicians have to help them."

Overestimation

The fear of leaving patients hopeless contributes to over-prognostication, Dr. Prigerson said, adding that there is often a three-fold overestimation of how long patients have to live, and patients tend to overestimate even more than their physicians do.

Abdulaziz Sachedina, PhD, a chaplain and Professor of Religious Studies at the University of Virginia, spoke on religious traditions at the end of life. He said he sees this as an opportunity for religion to step in: "Religious people usually negotiate their end of life more in acceptance than rejection of the final conclusion of the medical practice," he said. "So it really helps, even the health care providers somehow, to draw the line about when the treatment should terminate."

One consequence of overestimation is that it often leads to the use of intense, expensive treatments at the end of life. Only half of eligible patients are using hospice, and the use of aggressive chemotherapy at the end of life is on the rise, Dr. Block noted.

"One of the things we found is that when patients overestimate and oncologists overestimate, you think there's something to fight for," Dr. Prigerson said.

The data also showed that highly religious individuals as well were more likely to want aggressive treatment in the end.

"I think there is also this faith that 'my prayers would be heard, that I have been praying to God and if I am supposed to live longer, then I must make sure that everything possible has been done.' I think it's a very positive and constructive way of looking at it, but there is also this acceptance in the mind of the person who is saying that I must make sure I have done everything possible to live a healthy life," Dr. Sachedina said.

Dr. Caplan said that in such instances, it is once again up to the physician to disclose the reality of death at the end of life.

"Physicians can say we're not going to do futile things, impossible things, hopeless things; they have to draw some line when they are asked to do things that just don't make any sense."

When asked what the response of the religious community would be to the denial of treatment, Dr. Sachedina replied, "I think what the religion would teach is that prolongation of life is not the obligation of the medical profession—rather, it is the curing of illness, and therefore they should not be engaging in or unnecessarily obstructing letting nature take its course."

'The Multimillion Dollar Discussion'

Dr. Prigerson noted that not only do aggressive treatments at the end of life often adversely affect patients' quality of life, but there is also the cost-benefit issue.

Arthur Caplan, PhD: "Physicians have to offer reasonable descriptions of what's possible—they shouldn't be over-promising, and they can't be giving false hope."

"We call it the multimillion dollar discussion," she said, adding that data show that having these end-of-life discussions saves almost $1 billion for cancer patients overall in the last year of life because it is associated with significant reductions in ventilator use, resuscitation, chemotherapy, and other expensive interventions.

In preliminary analyses, her team is finding that one third of the Medicare budget goes to the last year of life, and that 80% of those costs are for hospitalizations and very expensive care in the last month of life.

"Physicians have to offer reasonable descriptions of what's possible," Dr. Caplan added. "They shouldn't be over-promising and they can't be giving false hope, but they also have to present information and let their opinion be known about what they think is the right thing to do."

Whose Responsibility?

The need for more education and research seemed to be the consensus of the symposium participants. Dr. Caplan remarked that physicians need to be

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educated about their rights as well as the rights of their patients at the end of life. Likewise, patients need to understand the importance of communicating their wishes with all parties involved.

He also said there should be more end-of-life care training in seminaries and more religious leaders assigned to work in hospitals.

Dr. Sachedina agreed, saying that physicians' awareness of the role of religion is very limited. "They [physicians] may not believe in the power of prayer, they may not believe in the communal support that sometimes comes in the form of religion, but it is worth taking these elements of the social support and psychological support more seriously," he said.

When asked where the responsibility of disclosure falls, Dr. Prigerson said it's an empirical question: "Oncologists really like to say that it's driven by the patients, and one of the main things I want to do is look at which of these parties is having a more significant impact."

Dr. Block and Dr. Prigerson are currently awaiting approval to conduct such a study. ■