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PEOPLE LISTEN TO PANEL SPEAKERS DR. AARON KHERIATY, PASTOR RICK WARREN, DR. NGUYEN, AND FR. SPITZER DURING THE DIGNITY AND COURAGE AT THE END OF LIFE CONFERENCE AT SERVITE HIGH SCHOOL IN ANAHEIM LAST YEAR

FACING END-OF-LIFE CHOICES HEAD ON

PALLIATIVE CARE PHYSICIANS SCREEN 'BEING MORTAL' TO PROMPT DISCUSSION

BY CATHI DOUGLAS

wenty years ago, recalls Dr. Joseph Son Nguyen, his dying uncle didn't know about end-of-life options. Suffering chronic pain, his uncle went from one hospital emergency room to another until he finally passed away.

Now a board-certified chaplain at UC Irvine Health, it saddens Dr. Nguyen that at the time his uncle was dying there was little understanding of palliative care and no specialized physician available to treat his uncle's chronic pain.

Death and dying as viewed from the existential, spiritual and medical points of view has come a long way since then, but still has a long way to go. That was the opinion shared by a panel of physicians at a Community Screening and Conversation held recently at UC Irvine.

Rev. Dr. Nguyen, together with Dr. Aaron Kheriaty, associate professor of psychiatry and director of the UC Irvine School of Medicine Program in Medical Ethics, were two of the four panelists at a Sept. 22 screening and discussion of "Being Mortal," a groundbreaking 2015 PBS Frontline film. The event was co-sponsored by Alzheimer's Orange County and Orange County Advance Care Planning Partners.

"There is little time in the medical student's curriculum for palliative care and very little preparation of physicians to do this [end-of-life] work," Dr. Kheriaty said. "Early on in a physician's training there is an avoidance of the whole subject, with no one wanting to use the 'd-word' [for dying]."

"Being Mortal" follows Dr. Atul Garande, a Boston surgeon and New Yorker writer, as he explores the lives of people facing terminal illness and their relationships with the physicians who care for them. In conjunction with Dr. Garande's book of the same name, "Being Mortal"

investigates the practice of caring for the dying, and shows how doctors - himself included - are often remarkably untrained, ill-suited and uncomfortable talking about chronic illness, pain and death with their patients.

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Social workers, ministers, priests and rabbis can make the issue of death and dying a more human one. But physicians are trained to fix things, solve issues and intervene, noted Dr. Nicole Shirilla, a Scripps Health palliative care physician. "There is very little training or preparation for a large part of our work in having conversations with our patients about mortality, death and dying. It's difficult for physicians to search their own mortality and limits and realize there is not a fix for every problem."

On the other hand, Dr. Shirilla's oncology patients welcome her and appreciate her honesty, she said. "We see our work as being there for our colleagues," she noted, "in helping to model some of the communications skills we gain through our particular training."

Doctors and patients both want hope, Dr. Kheriaty acknowledged, but many of them hope for a cure or a life-extending therapy. "Death is the last enemy of medicine, but all our patients will succumb to death. It helps physicians to realize that

hope can take many forms, and that we can help patients to live better and use time well in their last days."

In fact, he noted, terminal patients can use their remaining time to reconcile broken relationships, make amends to children or spouses, resolve remaining life issues and tend to their spiritual lives. "We recognize now that other things have a more essential role in the dying process than medicine, so we need to expand and take a new approach to medical training and practice for patients who cannot be cured."

Chaplains and clergy members play an honored and important role in care for the dying, said Dr. Nguyen, because they serve patients in a real, holistic and complete way. But palliative care should always be offered even if aggressive treatments are withdrawn, he added.

"We ask patients about their greatest joys, and that opens up a lot of insight into who they are as a human being in a holistic way," Dr. Shirilla said. "That heals families and the medical team to broaden the conversation and begin thinking about how these medical decisions have a context and how we make decisions about care."

Because end-of-life care often is decided well in advance of a final illness, advance directives are vitally important for everyone over 18 years old, panelists agreed, even though the document itself can be intimidating. Just 6 percent of UC Irvine patients had an advance directive.

The legal documents, they noted, are, after all, nothing if not prompts for important end-of-life conversations.

In absence of a printed document or even alongside one, it's critical for families to discuss end-of-life decisions, including naming a surrogate decision-maker for medical treatment, panelists agreed. Many times friends and family members can recall previous medical decisions the patient has made or prior conversations they have had, both of which can indicate their long-term wishes.

For the terminally ill, medical decisions "should be approached as a continuous process," recommended Dr. Kheriaty. "People should circle back and revisit their conversations and update their documents as their illness progresses or when they make specialized medical decisions." *