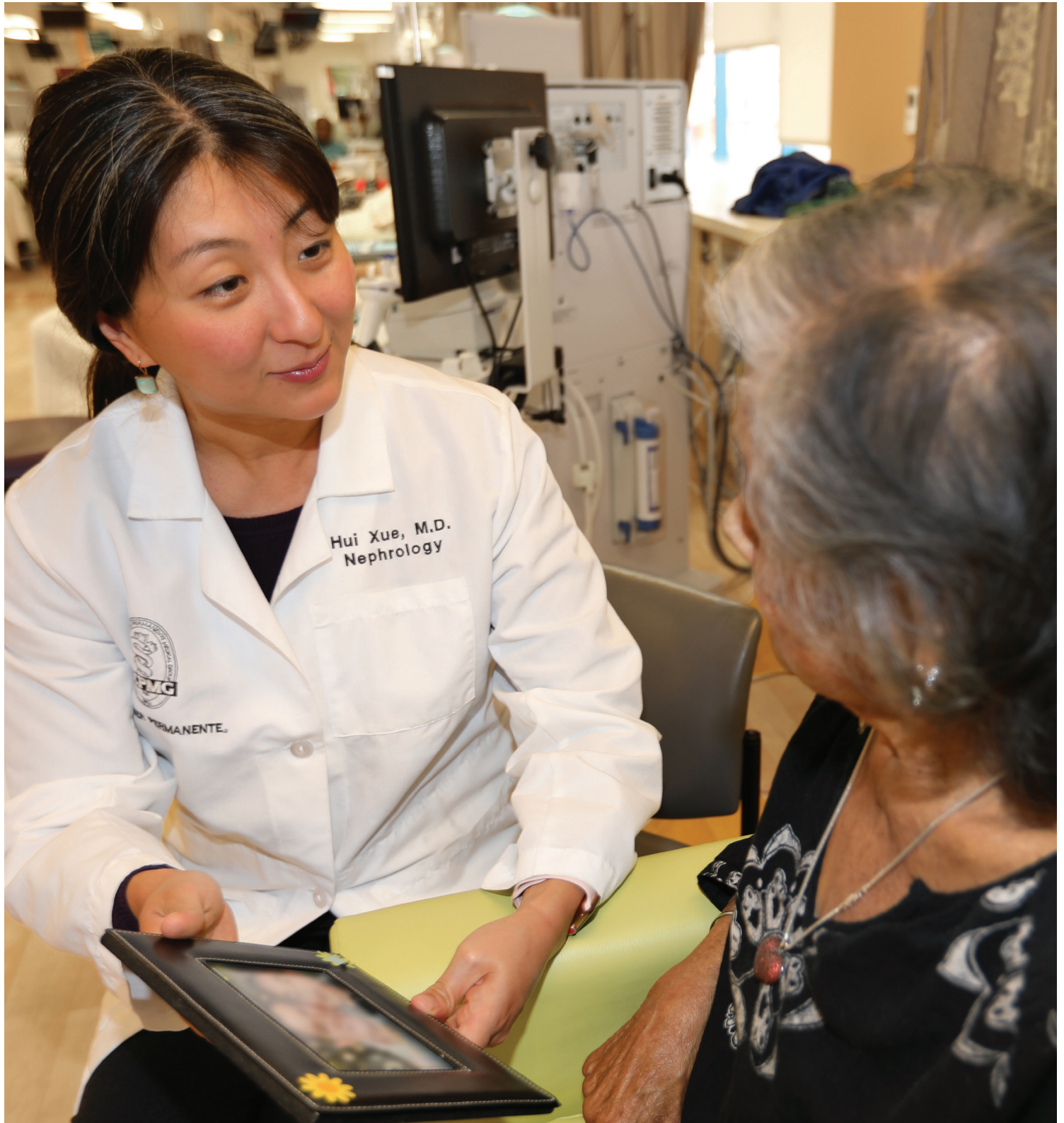


## End-of-life care:

Research is key to believing the best is possible



## Research Highlights

**T**he care patients receive at the end of their lives is often driven by anecdote.

For patients, the experience may be rooted in what they see in the media. For physicians, their decisions may be influenced by a lack of comprehensive training and limited personal and professional experiences with death.

"To improve the care experience at the end of life, we must believe that a good outcome is possible," said Susan Wang, MD, medical director of Life Care Planning for Kaiser Permanente Southern California.

"Research is the key," she continued. "The goal of medicine is to prevent, address, and alleviate suffering. But if we don't know better, we may accept that a low standard of care is 'inevitable.' For us to have a meaningful impact, we need more research to better understand which treatments, decisions, and services best meet the needs of our sickest patients."

### Research takes many approaches to end-of-life care

At the KPSC Department of Research & Evaluation, a number of researchers are working to make life transitions better for patients and their families including:

- David Glass, PhD, who has been working to determine if KPSC is giving patients the care they want at the end of life, and how to improve that care
- Huong Q. Nguyen, PhD, RN, who is starting work on increasing the efficiency, access, and care experience for home-based palliative care, including the integration of physician video visits
- Chun Chao, PhD, MS, who is researching the quality of end-of-life care for adolescents and young adults
- Hui Xue, MD, MMSc, a clinician investigator, who is researching how dialysis affects quality of life and longevity for elderly patients with chronic kidney disease

Care for seriously ill patients can encompass both palliative and hospice care. Palliative care, which can be provided in the clinic, hospital, and in patients' homes, is focused on providing relief from the symptoms and stress of a serious illness. It can be provided along with curative treatment. Hospice



Dr. David Glass has been working to determine if KPSC is meeting patients' needs as they approach the end of their lives.

care is a benefit provided to people with limited life expectancy who are not pursuing curative treatment, to optimize their quality of life.

### Inquiry: Are patients' end-of-life care wishes being carried out?

Dr. Wang recalls embarking on a study with Dr. Glass in 2015 to determine if patients' end-of-life care wishes were being carried out at KPSC. Those wishes include a patient and family deciding they no longer want life-sustaining measures, such as CPR, artificial feeding, or mechanical ventilation, to keep the patient alive.

"I see the mismatch between preference and treatment as very serious," she said. "But the culture of medicine is always to err on the side of survival, so, if a physician wasn't sure about a patient's wishes, they would always try to revive the patient even if that was not what the patient may have wanted."

Dr. Wang; Dr. Glass; Michael Kanter, MD, then-medical director of Quality and Clinical Analysis for the Southern California Permanente Medical Group; and others conducted the study to determine how well KPSC is meeting the end-of-life wishes of members by honoring their values and expectations.



The project started with focus groups with the next of kin of Kaiser Permanente members who had passed away. Previous research had suggested that next of kin didn't necessarily know what their loved one wanted before they died.

"But, these next of kin were adamant, no matter how we asked it, that they did have discussions with their loved one, they did know their loved one's wishes, and they did know how well we had done in meeting them," Dr. Glass said.

The researchers knew they could learn even more with a quantitative study. The team surveyed next of kin of 715 Southern California members ages 65 years or older who died in April and May 2017. The analysis and writing were completed in 2018 and the project will be presented at the Kaiser Permanente Quality Conference in June 2019.

Researchers found that nearly 85% of the patients had talked with their loved ones about their preferences. An equal proportion had filled out an advanced directive to document their wishes concerning medical treatments at the end of life. About 65% had spoken with a physician or staff about their end-of-life treatment preferences.

Almost 90% of the patients' loved ones agreed or strongly agreed that Kaiser Permanente gave "care and treatment over the last year of my loved one's life that met my loved one's wishes." The study also found that the cost of care at end of life did not necessarily equate to satisfaction with care at the end of life.

The investigators said the 2 factors that provided the best opportunities to better fulfill patient wishes were to better accommodate members' wishes to die at home and to hold more end-of-life discussions.



Dr. Susan Wang and nurse Kristin Olomu visit with 91-year-old patient Faye Crawford in her Los Angeles home.



At the West Los Angeles Medical Center, Dr. Susan Wang, Dr. Jason Ngo, and Dr. Andre Cipta discuss the importance of meeting patients' end-of-life wishes.

### Investigation to implementation: Achieving better connections in palliative care

When one of her studies found that palliative care services for patients going home from the hospital were limited and not always reliable, Dr. Nguyen obtained \$14 million in funding from the Patient-Centered Outcomes Research Institute in 2018 to test a more efficient model of home-based palliative care that integrates video consultations with physicians.

Dr. Nguyen's research into end-of-life care, which she prefers to call simply part of a patient's journey, compares a standard home-based palliative care model that includes routine home visits by nurses and physicians with a tech-supported model that includes video consultation with the physician.

"With the tech-supported approach, the nurse is in the patient's home and facilitates a video conference, so the physician can talk with the patient and the family in a synchronous way," Dr. Nguyen said. "We believe that the nurse and physician addressing the patient's and the family's concerns together will build the patient's and family's trust in the care team."

To determine whether video visits could be similarly effective for patients as the standard model, about 100 registered nurses were randomized to the 2 models so that approximately half of the patient-caregiver pairs are in each model.

Researchers will continue to recruit patients and their caregivers over the next 2 years.

"Video visits are not appropriate for all encounters, but we hope to better understand under what circumstances video visits are effective for patients and their caregivers," she said.

## Investigating end-of-life care for adolescents and young adults

As KPSC researchers look for ways to make life transitions better for all patients, some researchers are looking at very specific patient populations. Dr. Chao is studying those who are ages 12 to 39 years.

She conducted a pilot study of the more than 600 young people with cancer at KPSC who died between 2001 and 2010 and found that more than two-thirds received medically intensive end-of-life care. The findings led to Dr. Chao obtaining a grant in 2018 from the National Cancer Institute to expand the study to end-of-life care for 2,500 young people in 3 different health systems.

"Young people's end-of-life care has been very understudied," Dr. Chao said. "And, it is a very different thing for someone to face death when they are 20 versus 70. Many of the young people have not had a chance to realize their life goals and some are still trying to complete their education. It can be devastating for the patient and the caregiver."

Her previous work found that in their final month of life, young people were receiving chemotherapy and being put into intensive care more often than older adults.

"Is it because the patient really wanted it or does the doctor feel obligated to do those things? We don't know," she said. "But we believe that, by understanding the end-of-life care preferences of younger patients and their caregivers, we can improve the way care is provided for this group."

## Inquiry: What's best for aging patients with chronic kidney disease?

Dr. Xue, a nephrologist at the Kaiser Permanente San Diego Medical Center and a clinician investigator with R&E, is studying patients at the other end of the age scale, those who are 75 years of age and older, specifically those in the final stages of chronic kidney disease.

She targeted this group because as a physician she saw a gap in knowledge that only someone working at a place like Kaiser Permanente—with its integrated health care system and large diverse patient population—could answer.

"So, I'm looking at these people who are very near their life expectancy for individuals in America, right before they're about to go on dialysis," Dr. Xue said. "Are they going to live longer if they go on dialysis



Nancy Cannizzaro and Dr. Chun Chao discuss a study about end-of-life care.

versus if they don't go on dialysis and die from natural kidney function decline? And most importantly, what is the effect on their quality of life?"

The study of about 2,000 patients, with quality of life considered, found they gained about 7 months by being on dialysis.

"The group on dialysis had twice as many emergency department visits and twice as many hospital stays," Dr. Xue said. "Overall, it seemed like they had a harder life."

## Implementation: Sharing findings with other nephrologists

In 2018, the research was shared at a meeting with all the nephrologists in Kaiser Permanente Southern California, so they can all be better counselors for their older patients with chronic kidney disease. It will be submitted for publication in 2019.

Dr. Xue said that whenever she discusses end of life with patients she urges them to "not get lost in the trees. To take a step back and look at the forest." Focusing on every single small decision, each drug, each procedure, each small adjustment can be overwhelming for the patients and their caregivers.

"And it does not bring joy," Dr. Xue said.

Research can give patients a broader view of their potential and possibilities at the end of life, provide a more holistic view of what is ahead, and inform the larger decisions.

"Ultimately, the biggest questions people have are how long are they going to live," she said, "and how are they going to spend those days?"