FROM THE EDITOR

End-of-Life Care
Karen R. Horowitz, MD, FACP

Editor in Chief, SGIM Forum

In 2016, California, Colorado, and Washington, DC, followed the examples of Washington, Vermont, Montana, and Oregon in passing aid in dying legislation. According to a recent New York Times article, “it is now estimated that close to 20% of Americans live in jurisdictions where adults can legally end their lives [by choice] if they are terminally ill and meet eligibility requirements.” To honor the intent of these laws while providing the best possible care for our patients, it is imperative that end-of-life decision making be included in the skill set for every physician and healthcare provider.

In this issue of Forum, we asked palliative care experts to share their insights regarding end-of-life decision making in the 21st century. How can we encourage patients and families to have meaningful discussions among themselves about end-of-life planning? How can we guide patients toward care that honors their values and expectations? How can we avoid the futility of one more test, one more surgery, or one more retreatment?

As I read the article (in this issue of Forum) by Dr. Martin illustrating the last month of caring for her patient, Dr. B., I found my thoughts transported back in time to March 1991, when then SGIM member Dr. Timothy Quill published his story of Diane, a candid account of a terminally ill patient and her physician partnering in physician assisted suicide at a time when such practice was universally taboo. This publication triggered debates throughout the medical world as well as in the courts and continues to be referenced as a seminal moment in the national dialogue on this important topic. A grand jury was convened to review the events of the case and consider initiating criminal indictment of Dr. Quill, but in the end decided against doing so. As I reflect on these two stories, I marvel at how far we have come in 25 years! And yet, for physicians and patients, the challenges remain largely the same.

For some patients, it is extremely difficult to know when to let go. As physicians, we are aware that the prior probability of a poor outcome increases with advancing age and frailty, yet we often fail to include these risks in our discussions with patients as we discuss long-term plans of care. Our seniors have witnessed amazing things in their lifetimes: the invention of penicillin and eradication or control of many infectious diseases, cardiac surgery, hemodialysis, cancer cures, and organ transplantation…. Is it any wonder that at no matter what stage of life, continued on page 2
MOC Made Easy at the SGIM National Meeting
Eric H. Green, MD, MSc

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This year, for the first time, maintenance of certification (MOC) credit will be available to all ABIM-certified physicians who attend the SGIM 2017 Annual Meeting. SGIM has capitalized on changes to the MOC program to allow meeting attendees more flexibility in obtaining MOC credit. At this year’s annual meeting in Washington, DC, SGIM and its CME partner, the University of Alabama at Birmingham, will offer MOC credit for all CME hours granted. There will be no added fee for MOC, and SGIM members will not need to complete multiple-choice questions based on the content of the sessions they attend.

Conference attendees will still be required to apply online for CME credit after the meeting. Attendees who wish to receive MOC credit will be directed to answer additional global questions describing how they will use the knowledge and skills obtained at the annual meeting in their practice. These will be presented as a link to MOC questions at the end of the online annual meeting evaluation. Attendees who complete this process will be awarded 1 MOC “point” for each hour of CME.

What do you need to do to get MOC at the annual meeting? It’s as easy as 1-2-3!

1. Before you go to Washington, read the e-mails from SGIM that provide the MOC questions.
2. While you are enjoying the meeting content, think about the MOC questions.
3. When you receive the meeting evaluation complete the MOC questions.

See you in Washington, April 19-22, 2017!
Turning Up the Volume on SGIM’s Voice
Eileen E. Reynolds, MD

I’m working on my March column today—January 20th, Inauguration Day. In many ways, we don’t know any more today about how the new administration will impact our patients, our practices, and our hospitals than we did on Election Day.

In a post-election e-mail to members, I wrote “SGIM will continue to promote goals consistent with our mission, and to advocate for policies and programs that foster social responsibility in health, healthcare, and diversity. We will be particularly focusing our efforts and advocacy on preserving and promoting universal access to healthcare as we anticipate attempts will be made to repeal or weaken the Affordable Care Act in early 2017. We believe access to healthcare is a fundamental right and that keeping Americans healthy strengthens our economy, families, communities, and security.”

Later, in my January Forum column, I suggested two New Year’s Resolutions for SGIM:

1. SGIM will strive to keep members informed about policy changes and advocacy opportunities; and
2. SGIM will work to broaden our reach and strengthen our voice by engaging with other organizations interested in advocating for preserving and promoting access to health care.

Ironically, I’m working on my March column today—January 20th, Inauguration Day. In many ways, we don’t know any more today about how the new administration will impact our patients, our practices, and our hospitals than we did on Election Day. Mr. Trump just signed a multi-part executive order that stated the administration’s official policy is “to seek the prompt reappearance” of the Affordable Care Act. But how much can and will be repealed, and what it will be replaced with, remain a mystery.

SGIM has been working hard on New Year’s resolutions. We want to be ready to respond as a nimble, effective organization. The following ways illustrate how we are adapting our work to support patients and their access to care, members, and their access to information:

1. **We have updated our advocacy platform.** SGIM’s advocacy platform is typically updated annually in June, and is written by our Health Policy Executive Committee and our colleagues at CRD Associates (http://www.dc-crd.com), then formally approved by Council. This year, Council voted to update our platform during our December council retreat. We moved “clinical” areas to the top to signify their leading importance and added “active advocacy” in areas that had only been “monitored.” Here is our new highest priority item:

   “The implementation of comprehensive health care reform under the Affordable Care Act (ACA) has fundamentally improved how patients obtain insurance and access care. As Congress develops legislation to repeal the ACA and replace it with an as yet undefined set of “reforms,” SGIM will advocate to ensure that patients continue to have access to affordable health care services. Any future reforms targeting access to insurance and payment models must continue to improve patient access to needed, quality health care services. (Active Advocacy, Coalition Advocacy, Monitoring).”


2. **We have expanded Hill Day.** Hill Day will be taking place on March 7-8th. Many members may not realize that advocacy is expensive for our organization! Last year, in an attempt to control costs, SGIM had planned to limit our Hill Day program to only 25 members in order to continue on page 10
The number of patients suffering from chronic illness continues to increase; however, advances in technology often promote longevity, but not necessarily optimal quality of life. Two life-limiting illnesses that often raise the question of how to balance quantity and quality of life are advanced dementia (AD) and end stage renal disease (ESRD). Prognostic uncertainty and unpredictability are common to each of these conditions. Both AD and ESRD are especially challenging for clinicians trying to guide families through difficult decisions about the use of artificial nutrition and hydration (ANH) or initiating hemodialysis (HD). Many clinicians lack an understanding of the evidence for and against initiating these aggressive interventions in such patients. Given that this level of uncertainty can cloud the picture of the true benefits of these treatments, patients and families are often inadequately prepared and empowered to make fully informed decisions. In addition, many providers lack the communication skills training required to discuss patient and family values that should guide these decisions or are not trained to convey the idea that less aggressive interventions can improve quality of life, without hastening death.

Dementia is an extremely common condition affecting 24.3 million people worldwide, and is anticipated to affect 13.2 million in the US by 2050. In the United States, it is also the fifth leading cause of death for people over the age of 65 years with Alzheimer’s disease being the most prevalent type, followed by vascular, Lewy Body, and other rarer forms of dementia. Feeding difficulty in AD is common, with 85.8% of nursing home residents with AD experiencing eating problems in a retrospective study.

What is often underappreciated is that AD is a terminal condition with a six month mortality of 25% and a median survival of 1.3 years. This life expectancy is similar to better recognized terminal conditions such as metastatic breast cancer and advanced congestive heart failure. Despite this limited life expectancy, a growing number of patients with AD are receiving feeding tube placement for their eating problems. There are many factors that influence the use of feeding tubes, including absence of advance directives, legal and regulatory fears of nursing home administrations regarding weight loss, and the Medicare and Medicaid reimbursement models for feeding tubes. More concerning are the misperceptions of the value of feeding tubes by the clinicians who are helping families to manage this challenging decision.

A survey of primary care physicians from the AMA Masterfile in 2003 showed that a majority of physicians who responded felt that a percutaneous endoscopic gastrostomy (PEG) tube reduced aspiration pneumonia, improved pressure ulcer healing, improved survival, and was the standard of care. A survey of family members reported that in cases where patients had a feeding tube inserted, 13% reported that a physician had no discussion with the family about insertion, and when he/she did, 41% of the conversations lasted less than 15 minutes. Further, 52% of families felt the clinicians strongly favored feeding tube insertion.

These experiences are in sharp contrast to what the literature actually says. A Cochrane review of six observational studies showed no evidence that enteral feeding prolonged survival, improved quality of life, enhanced nutrition, or decreased the risk of pressure ulcers. Other studies concluded that patients who had a feeding tube inserted were more likely to develop pressure ulcers, did not have a reduced risk of aspirations, had increased use of restraints, and required more hospital days. In addition, 20% of patients required replacement or repositioning of the tube. The periprocedural mortality of patients with dementia who undergo PEG tube placement is 6–28%, and 64% die within a year after placement, with a median survival of only 56 days. Patients with feeding tubes may be isolated and lose the social stimulation that accompanies hand feeding. AD continues to follow its natural course regardless of interventions we may be able to perform. Our professional challenge is to support patients and their families while providing accurate information about the role of artificial nutrition in AD.

As with dementia, physicians seem to have misunderstandings about the burdens and benefits of hemodialysis in frail elderly people. Patients over the age of 75 years are the fastest growing group undergoing HD initiation in the United States. However, mortality exceeds
Mrs. R is an 82-year-old woman with advanced dementia, seizure disorder, chronic dysphagia, and malnutrition with recent weight loss and sarcopenia. She is able to transfer independently from bed to wheelchair at baseline; she was admitted after an unwitnessed fall at her memory care facility with a displaced femoral neck fracture. After discussion between the orthopedics team and her son, she underwent a successful left hemiarthroplasty. Post-operatively, she developed acute blood-loss anemia, hypotension, and delirium. Further discussion with her son revealed a steady course of decline over the last year; Mrs. R had had repeated hospitalizations for seizures, UTI with bacteremia and delirium, and falls. After each hospitalization and subsequent stay in rehab, she never seemed to reach her prior cognitive nor functional baseline. Now, she could only intermittently recognize her family, and her ability to speak had declined such that she was only able to state one short phrase at a time. After further reflection on Mrs. R’s life and her previously completed Advance Directive, Mrs. R’s family decided that she would not want to live the last years of her life bouncing from hospital to skilled nursing facility and back again. They decided to enroll her with hospice and forego yet another stay in skilled rehab. She received two units of red blood cells, one liter of normal saline, and her pain was controlled with low doses of oral oxycodone and scheduled acetaminophen. She was discharged home to her memory care facility with a hospice intake appointment upon arrival.

Despite the surgical advances and improvements to care in the last 20 years, hip fracture remains a life-altering and potentially devastating event for more than 200,000 older adults every year.¹ Mrs. R’s story feels familiar because it is common for a hip fracture to mark the final chapters of someone’s life. Femoral neck fracture is the flagship fragility fracture and it is just that—fragility—that comes to define the often prolonged, tumultuous recovery. Knowing this, a question arises: Are we doing enough to acknowledge and consider frailty from the day of the fracture? In 2014, Fred Ko and R. Sean Morrison coauthored an excellent editorial calling for integrating palliative care teams alongside the interprofessional team in the care of frail hip fracture patients, an approach designed to replace our current model of separating curative and palliative care.² We agree that a holistic focus on symptom management coupled with discussion around goals and care coordination, provided concurrently with standard care, provides an excellent framework for patient-centered care. When palliative care consultants are available in the hospital, we highly recommend involving them early. Here, we propose the following four strategies to improve the care of elderly patients with hip fracture by incorporating palliative care principles in the acute care hospital setting to be implemented as soon as frailty has been identified:

1. Inquire about the patient’s recent functional trajectory and goals for care upon admission.

Beyond an advance directive or POLST form, we should get a sense from every hip fracture patient and/or their caregivers about their functional status, living situation, burden of chronic disease, and priorities for the rest of their lives. Incorporating these questions into our standard work will stratify the frail from nonfrail, assist in our ability to prognosticate, and enable the task of providing advice and guidance to be more straightforward. We often start by asking about an advance directive and/or POLST followed by questions that promote reflection on previous experiences and identify priorities for the remaining years of the patient’s life.

2. Assess prognosis and provide clear, thoughtful information about the future. Prognosis lends context to the clinical advice we offer patients. It is the difference between an arthroplasty or pinning, or no surgery at all. It is the difference between planning for a stay in post-acute rehab versus going home with hospice. In large part, the treatment plan for a hip fracture patient depends on our collective sense of prognosis; however, prognostication has generally been difficult for conditions other than cancer or heart failure. New tools such as UCSF’s ePrognosis (eprognosis.ucsf.edu) have simplified validated prognostic scales into a collection organized by clinical setting that is quick and easy to use.³ Clinical judgment remains the cornerstone of prognostication but can be strengthened when coupled with an applicable and validated prognostic scale.
As primary care physicians, we witness our patients aging before our very eyes. Where a 72-year-old patient would once come bounding down the hallway, fifteen years later he/she is now using a walker and taking 10 minutes to enter the exam room. We face questions from concerned adult children about whether their parents—our patients—are safe to live, drive, or manage finances alone.

Even closer to home, as adult children ourselves, we witness our own parents aging. For many physicians, our parents are our number one patients and, as they age, we become more concerned. They may look well, but they are moving slower, needing to have us repeat ourselves more, and requiring reminders of things. This is all part of the aging process. However, it is shocking how few people anticipate or plan for the 10 to 20 years before death, which is often termed the “Fourth Quarter of Life.”

Many of us talk with patients and their families about powers of attorney, goals for care, making end-of-life decisions, and palliative care. As physicians, we will likely have these conversations with thousands of aging patients and families. What we may be unprepared for is how to offer patient-centered advice for this Fourth Quarter of Life.

Over a lifetime, people commonly plan for milestones, such as education, marriage, children, housing, 401K investments, and retirement. Some of my patients have even selected caskets and made funeral arrangements to ensure that their funerals will be exactly what they want. Unfortunately, many do not consider advance life events (ALEs) or health emergencies, such as a hospitalizations, falls, or memory loss that will likely throw their lives into a melee.’

When ALEs happen, patients and their families often look to their trusted internist or geriatrician for advice. Repeatedly, as a geriatrician, I am asked many questions, including “Mom fell and is hospitalized now, do you know what we should do to help her get home?” or “Do you know any good SNFs (skilled nursing facilities)?” or “Does she need a caregiver and how do I find one?” or “How am I to pay for all of this?”

After participating in this conversation umpteen times with each crisis, I thought “why do we have to merely react to the aftermath of a crisis when we know that it might happen?” and “Why do we fail to plan for these events?” We know that seniors may be hospitalized at some point. There is a fair chance that they may fall. There is a significant possibility that their memories will worsen.

Individuals age 65 and older have a 68% lifetime probability of becoming disabled in at least two activities of daily living or of being cognitively impaired.’ And by 2050, approximately 27 million people will be using paid long-term care services in some setting, such as at home or a residential care setting, assisted living, or skilled nursing facilities.’

Why do seniors and their providers avoid discussions regarding long-term care services they will need as they age? Why don’t we make decisions for the future, just as we do for end-of-life planning?

We should plan to age-in-place safely before a crisis occurs.

PlanYourLifespan.org is a free-to-use, nationwide Web site tool developed by my team of geriatricians, nurses, social workers, communication experts, seniors, and caregivers at Northwestern University Feinberg School of Medicine to help seniors and their families plan for their Fourth Quarter of Life. By using PlanYourLifespan.org, seniors and their loved ones will learn about common ALEs that can impact their independence. By entering their residential zip code, they can find and access local resources that can help them now or in the future. For example, some of the choices and information include the following:

• What are the rehabilitation options available to me after a hospitalization?
• Am I prepared to return home after a hospitalization?
• How can I connect with local services and resources such as in-home care, villages, and skilled nursing facilities?
• What steps can be taken to help prevent falls?

The Web site interface incorporates large-font, high-contrast text and videos of actual seniors discussing their own experiences. After going through PlanYourLifespan.org, people can save their choices, print them to distribute to others, and/or e-mail their plans to loved ones. The communication component of PlanYourLifespan.org is crucial. Seniors can make exceptional plans...
SUPER: A New Framework for Goals of Care Communication

Niharika Ganta, MD MPH, Laura Dingfield, MD, and Nina R. O’Connor, MD

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Communication about goals of care is central to the patient-provider relationship. Clear exchange of perspectives allows patients to express their understanding of their medical care and expectations moving forward. Clear communication also enables providers to share realistic information about prognosis and disease trajectory with the goal of delivering care that is consistent with each patient’s unique goals. When this communication is skillfully navigated, patients feel supported and aligned with their medical team. Despite the importance of goals of care communication, very few physicians receive formal training in leading these difficult conversations.¹

Goals of care communication can occur at any time during a serious illness, and these conversations are associated with increased likelihood of goal-consistent care, improved quality of life for patients, and improved family outcomes.² Simple tools are needed to guide goals of care conversations in multiple settings by different members of the healthcare team.

SUPER Framework

The SUPER framework was developed as a patient/family-centered tool that encompasses both communication of medical information and discussion of patient values. SUPER is an acronym that stands for Setup, Understanding, Priorities, Explain, Review & Recommend, and described as follows:

Setup. This first step reminds clinicians to prepare for goals of care communication by reviewing medical records, speaking to other providers, and ensuring that key stakeholders, such as surrogate decision makers, are present. This step also includes finding a quiet and private setting for the conversation, minimizing interruptions, and having adequate seating. The actual conversation begins with introductions of everyone present.

Understanding. The next step is to assess patient/family understanding of the medical situation. By listening to the patient or family’s summary, the provider can assess for knowledge gaps. Providers should allow the patient/family to express their view without interrupting. Interruptions may discourage the patient/family from openly sharing, and the provider will have an opportunity to correct discrepancies later in the conversation. This step also allows providers to assess a patient or family’s health literacy so that information can be best tailored to the audience at hand.

Priorities. This step allows the provider to build a rapport with patient/family and remain focused on nonmedical goals and values. The patient/family is encouraged to discuss their hopes and fears regarding medical care while the provider engages in active listening. In addition, the patient can discuss any treatments that would not be consistent with their notion of good quality of life. For instance, a patient may express that he/she is willing to receive all treatments but would never agree to living in a nursing home. This step communicates to patients and families that the medical team cares about the patient as a person and that treatment plan must fit within the context of the patient’s entire life.

Explain. This step turns the spotlight to the provider. The provider should fill in knowledge gaps and provide prognosis, if known. Providers must avoid medical jargon, speak in simple and short sentences, and pause frequently to allow listeners time to process information. This step is especially effective if the priorities shared in the previous step are woven into the medical information. For instance, “Your heart disease is getting worse. I worry that you may not make it to your granddaughter’s graduation, which is very important to you.” The provider can share any barriers or threats to achieving the patient’s stated goals; for example “Let’s think about what needs to happen for you to go home as hoped.”

Review and Recommend. The last step is to review the discussion points to ensure that everyone is in agreement. It is important to highlight the key medical issues and patient/family values. At this time, the provider synthesizes the clinical situation with patient/family wishes to continued on page 11
In August 2016, I met a retired physician in his 80s who was dying of prostate cancer that peppered his entire skeleton, compressing his spinal cord. He had just been discharged from the hospital to the skilled nursing facility, part of the senior community where he had lived for a decade, and I became his physician there. At that first visit, he was quiet, thin, gracious, and in pain. A few days later, Dr. B- and his son invited me to close the door and sit with them. They asked me about dying. Dr. B- knew how he wanted to go—by taking medication on a day of his choosing that would quickly put him into a sleep from which he would never wake. He had heard that doctors sometimes helped patients with this unofficially, and wondered if that was the best way, or did I know anything about California’s new law permitting physicians to prescribe medication to aid in dying? At times when I’ve encountered uncertain moments in physician-patient-family discussions, I resorted to “duck” mode—placid demeanor above, furious churning below. (“Oh no, where can I find my hospital protocols about the new law? Why didn’t I pay closer attention when it was discussed?! Can I, should I, will I do this?”) Dr. B- let me know that he had a few weeks’ worth of loose ends to tie up and family and friends to hug goodbye, and then he would be ready. I excused myself to get him brochures about the End of Life Act (EOLA) in California, closed the office door, and sat for a few minutes with the churning inside my head.

As a geriatrician, I’m a dedicated advocate of palliative and hospice care during the last months of life. Many of my patients die in their homes or long-term care facilities under hospice care, for which patients and families are typically very grateful. The EOLA had just become California law. I passively supported this individual right, but told myself and others that if hospice care were done properly, no one would need to avail themselves of this option.

After I frantically searched for the protocols to guide me through the labyrinth of steps that is the EOLA process, I went back to Dr. B-’s room and advised him to start hospice care. At minimum, the hospice team would help manage his severe bone pain during the required 15-day waiting period between his EOLA request and receiving the prescription. He agreed, and I was quietly thankful for the time I now had to internally process these events.

We increased the opiate doses. Intense bouts of nausea ensued, along with odd, powerful myoclonic jerks. These required clonazepam, which made him sleepy when he wanted to be alert to enjoy his grandchildren visiting from the east coast. He developed unrelenting hiccups. It became hard to tell which symptoms were from his aggressive cancer and which from the medications intended to provide him relief.

Initially, when I visited Dr. B-, he was wide-eyed with pain. Mercifully, with the hospice team’s help, the pain lessened. But his intention to take the medication to end his life did not lessen. I kept hoping he would change his mind, as his weight dropped steeply and his temples came into sharper relief. I believed he might not last the 15-day waiting period.

But he did. On day 15, a retired physician, close personal friend, and pool table adversary came to visit Dr. B-. Dr. B-’s son and his friend witnessed him sign the document stating that he wished to take a prescription medication to end his life. Although three of us were physicians, this decision did not feel at all medical—it was an experience of intense, life-affirming gravity, and, to me, it now felt completely right.

Over the days preceding, a physician colleague familiar with the legislation helped me find everything available about the medication options, how to prepare and take the medication, and what to expect. My worst nightmare was that something would go wrong at this critical moment in the life of Dr. B- and his family. I was reminded more potently than ever that this moment has an importance approaching that of birth, yet shepherding mothers and babies through that transition is performed by highly-trained clinicians. I was not alone, however, thanks to physicians in other states who had shared their knowledge through advocacy organizations. This was not something I could look up on UptoDate.

At the last minute, there was a surprise—the medication used most commonly for this purpose has been secobarbital, which would cost $3,700 because the manufacturer doubled the price one month after the physician aid-in-dying legislation was proposed in California. I called a dozen pharmacies to see if any could compound a new regimen from Washington state consisting of high doses of diazepam, propranolol, and morphine powders, at a fraction of the cost of secobarbital. The pharmacies were as unprepared as I was for the practical requirements of this new law.

We decided to use secobarbital because it was more readily available. Dr. B-’s son paid for it without telling his dad the cost, and drove an hour each way to the nearest pharmacy that could supply it within 48 hours. He then carefully cut and tapped out the powder from 100 capsules. If this seems like a painful burden to place on an already grieving family member, it is. But we were carried along by the Dr. B-’s
When Enough Is Enough: Guiding End Stage Renal Disease Patients through Cessation of Dialysis

Nina O’Connor, MD

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M K is a 62-year-old male with diabetes and hypertension who has been on hemodialysis for almost 10 years. He underwent a right below-the-knee amputation last year for a nonhealing wound and osteomyelitis. More recently, he has had two hospitalizations for sepsis from presumed line infections. Imaging for back pain now leads to a new diagnosis of Stage IV prostate cancer with widespread bone metastases.

In 2013, more than 117,000 new cases of end-stage renal disease (ESRD) were diagnosed in the United States.1 The total number of patients with ESRD continues to rise by about 21,000 cases per year, and more than 80% of ESRD patients receive hemodialysis.1 Dialysis patients have substantially higher mortality than patients with other chronic illnesses, including diabetes and cardiovascular disease.2 The elderly on dialysis have especially poor prognosis. Dialysis patients over age 75 have a one-year survival of 53% and spend 20% of their time in a hospital.2

Patients may contemplate stopping dialysis for many reasons. Some patients for example suffer a catastrophic event, such as a stroke or heart attack. Other patients develop a second life-limiting illness, such as cancer. For some patients, declining functional status and quality-of-life prompt questions about whether dialysis should be continued. One large study of nursing home residents reported substantial and sustained decline in functional status in the year after dialysis initiation.3

Unfortunately, very few ESRD patients have talked to their physicians about end-of-life preferences. Most advance directives fail to capture circumstances in which an ESRD patient would no longer want dialysis.

Despite perceived barriers to raising this difficult topic, data suggests that ESRD patients want more conversation about end-of-life options including stopping dialysis. The Renal Physicians Association has affirmed a patient’s right to stop dialysis and encourages physicians to use a shared decision-making model when discussing this option with patients and families (see Table 1).4

<table>
<thead>
<tr>
<th>Clinical Situations in which Cessation of Dialysis Should Be Considered</th>
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<tr>
<td>• Request to stop dialysis by a patient with decision-making capacity</td>
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<td>• Request to stop dialysis by the legal surrogate of a patient who lacks decision-making capacity</td>
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<td>• Irreversible, profound neurological impairment</td>
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<td>• Inability to cooperate with the technical process of dialysis (e.g., advanced dementia patient who pulls their dialysis needles)</td>
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<tr>
<td>• Unstable condition that makes dialysis difficult (e.g., hypotension)</td>
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<tr>
<td>• Development of a non-renal terminal illness</td>
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One study of 1,947 patients who enrolled in hospice after dialysis discontinuation reported a mean survival of 7.4 days (range 0-40 days).5 Two older studies both reported a mean survival of 8 days (range 1-46 days).5,7 The wide range in survival in these studies likely reflects residual renal function which is difficult to assess while patients are still receiving dialysis. Among patients who do stop dialysis, certain clinical factors can be used to predict survival when counseling patients and families (see Table 2).5

Patients who discontinue dialysis often experience pruritus, anorexia, and progressive somnolence due to uremia. They are also prone to volume overload, resulting in pulmonary edema, peripheral edema, and secretions. Diuretics are unlikely to be effective, so dyspnea should be treated with opioids instead. Respiratory secretions can be treated with anticholinergic medications, such as glycopyrrolate, scopolamine, or hyoscyamine. Myoclonus sometimes develops due to electrolyte abnormalities or accumulation of medications including opioids. If myoclonus causes distress, it can be treated with benzodiazepines. Agitation...
allow us to hold training in our own office, limit the costs of CRD’s extensive and essential work to arrange meetings on Capitol Hill, and free up SGIM staff to work on their other projects. When that decision was made, no one foresaw the current climate around many issues central to our organization. Therefore, in December, the Council voted to expand Hill Day up to a potential total of 70 participants. As a result, the staff found larger space at a reasonable price, CRD agreed to expand the scope of their work with us, and SGIM staff agreed to dig in, as they always do. The Health Policy Committee will be reaching out to encourage attendance from members who reside in states or districts where active advocacy may be most important and valuable. (I live in Massachusetts; while I love going to Hill Day, I’m hardly influencing Elizabeth Warren and the rest of the Massachusetts delegation to vote differently about health care, inclusion, or biomedical research funding).

We are also expanding our expectations for members who attend Hill Day by asking members to sign a “memorandum of understanding” that commits them to follow up on e-mails, calls, and visits with staffers.

In addition to Hill Day in Washington, we hope that many members will participate via “Off the Hill Day,” advocating in district congressional offices on the same day or days as Hill Day itself. We will produce a webinar for members that will include instructions and tips for Off the Hill Day participants.

3. We have expanded LEAHp. The new, year-long Leadership in Health Policy (LEAHp) training program is scheduled to begin with its first cohort at the Annual Meeting in April. Last June, Council provisionally approved the budget for a 10-member initial LEAHp cohort, with the “provisional” being based on concern about successfully recruiting 10 members. Well, at the December application deadline, 41 members had asked to join, far exceeding our initial hopes. We have approved LEAHp’s expansion to 20 members in the first year. It is our hope that LEAHp-trained leaders will staff our health policy committee, write white papers during their year, and lead our advocacy efforts for years to come.

4. You will be receiving Quick Hit Updates. Together with CRD Associates, our Health Policy Committee will be reaching out to you at least monthly via direct e-mail when there are urgent health policy action items for you to know about. In addition to the new, regular “Quick Hits,” the written health policy briefing summaries we receive from CRD will now be written in language that is accessible for non-policy-expert members (like me). Those summary update reports will be sent out via GIM Connect and can also be found on our Web site at https://www.sgim.org/communities/advocacy/advocacy-reports.²

5. Breaking News policy session(s) added to Annual Meeting. The deadline for workshop and symposium submissions to the Annual Meeting was months ago, before the election. That means that most rooms were already booked and the sessions were predetermined. As always, a number of policy-related workshops, abstract sessions, and interest group meetings were accepted and scheduled, but their content was submitted and finalized before the submission deadline. Because there will be fast-moving changes in Washington that affect our policy agenda, we have found space for sessions that are specifically reserved for breaking news/updated content. Register for the annual meeting here: http://connect.sgim.org/sgim17/home.

Unfortunately, Congress will not be in session during the meeting, but we will provide instructions on how to schedule a Hill Visit with your congressperson’s office staff for members who are interested in doing so.

6. Council has voted to hire a physician leader for SGIM. It’s been a tumultuous year for SGIM in terms of leadership. We hired an Executive Director (ED) last spring, and Kay Ovington returned to her role as Chief Operating Officer after a very successful year as Acting ED. But, it turned out that the ED we hired did not have a great skill match for our needs, and so (after lots of feedback and coaching) we asked him to leave in early December.

As Council reflected on the experience, and on how to move forward, we concluded that our best opportunity to exert and extend influence and to “broaden our reach and strengthen our voice” would be to have a longitudinal, part-time employed physician leader as SGIM’s external face to partner with Kay’s very capable and committed internal facing leadership. We are excited about the opportunities that a highly respected and effective physician leader can bring to our longitudinal relations with external allies like the ACP, AAIM, and the new Primary Care Collaborative and to our voice on Capitol Hill!

In all of SGIM’s work, we rely on our members to be our loudest voice. I hope that this list of advocacy enhancements will engage, motivate, and focus SGIM members in the hard work that lies ahead.

References
make a recommendation about next steps. For instance, if a patient with end stage heart failure values freedom from symptoms, spending time with family, and dying at home, an appropriate recommendation might be home hospice services. Aligning the recommendation for next steps with patient/family values increases the likelihood of patient/family agreement with the proposed plan. If the recommendation is not accepted, the provider can respectfully explore questions or hesitations. An acceptable alternative may surface. If not, the provider should establish a plan to reconvene at another time to revisit the patient’s condition and patient/family priorities. The conversation should always end in agreement.

Applying SUPER to Clinical Practice
SUPER is designed to create a forum for patients and families to openly discuss their wishes and values for medical care. It is an effective framework for family meetings, but can also be used for shorter screening goals of care conversations. For example, a provider can move through the sequence in 10-15 minutes to screen for knowledge gaps and discrepancies between patient/family goals and current treatments, and a longer discussion can be scheduled with family if needed. SUPER can also be used to guide discussions about code status. A brief discussion about priorities enables the provider to make a recommendation for code status that is grounded in both the patient’s prognosis and the patient’s values. An informed recommendation shifts the burden of decision making away from patient or family.

Adapting SUPER for Various Disciplines and Levels of Training
The SUPER framework can be used by clinicians from many disciplines, and at different levels of training. SUPER can be used in its entirety, incorporating all five steps, or components can be used based on the user’s comfort and training level. For example, nurses are well positioned to use SUPER to assess patient and family understanding of disease status, as well as hopes and goals as part of informal conversations during routine care. Similarly, the initial steps of SUPER do not require detailed knowledge about prognosis or treatment options, so the tool can be adapted for goals of care conversations by junior providers and trainees. At our institution, we have successfully taught SUPER to experienced physicians, resident and fellow trainees, medical students, advanced practice providers, registered nurses, and social workers.

Discussion
The SUPER tool is simple to use, encourages patient/family involvement, and empowers providers to synthesize clinical information with patient values to make treatment recommendations. Moreover, SUPER allows providers to conclude goals of care discussions with agreement. Additional work is needed to determine impact on patient outcomes and family satisfaction, but the intuitive nature of this tool merits circulation for widespread use.

References
3. Strive for optimal pain control. Undertreated post-operative pain is significantly associated with the development of delirium (RR 5.4), delayed ambulation, longer lengths of stay, and long term mobility restrictions. Prior to ortho-geriatric co-managed care, a hip fracture patient with dementia was far less likely to have a standing analgesic order because his/her recall of pain is often limited to that point in time. Additionally, multifactorial, post-operative hypoactive delirium can present with somnolence which can be mis-interpreted as an adverse effect of opiates, when in fact uncontrolled pain may be driving the hypoactive state. Orders for post-operative pain control commonly call for a range of opiate dosing as needed while adju nctive agents such as scheduled acetaminophen, heating pads, lidocaine patches and non-steroidal anti-inflammatory creams are underutilized. Judicious attention to nonverbal pain indicators, consideration of scheduled opiate doses in patients with difficulty communicating pain, and liberal use of adjunctive agents can improve pain control in patients with impaired cognition. We recommend Tylenol 1000 mg three times a day (assuming preserved liver function) and a low dose oral opioid like oxycodone or hydromorphone every 3-6 hours with close eye on usage in the first 24 hours post-operatively.

4. Reconsider the presumed pathway of hospital to SNF to long-term care. With increasing age, medical complexity, and advanced cognitive impairment, many older adults do not benefit from intensive physical and occupational therapy to the same degree as their younger, or more fit, counterparts. Furthermore, transitions to an unfamiliar setting with new providers increase the risk of both worsening disorientation and psychological discomfort. In addition, adverse drug events with transfer from hospital to long-term care which are common including risks that agents can be inadvertently omitted, dose adjustments missed or held or prescriptions not restarted. Families often report not knowing that any other pathway exists, but demonstrate palpable relief when an alternative focus on comfort, rather than intensive rehabilitation, is proposed. Initiation of home health therapy or hospice in place of a short stay at skilled rehab may allow a frail but otherwise well-cared-for patient continue to live in a familiar setting with known caregivers.

In summary, hip fracture often heralds a downward trajectory in physical, cognitive, and emotional well-being in frail older adults. Thoughtful implementation of palliative care principles may assist clinicians in shifting focus away from an automated plan of standardized care toward a more patient-centered approach.

References

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determination to die in the way he believed best and his strength fortified us as we walked by his side.

On September 1st, Dr. B- refused his wheelchair, and propelled himself using a walker up a small hill from the skilled nursing facility to his apartment in the senior community. He did not wish to have any physician or hospice staff with him. His two sons and two brothers sat by his bedside when he swallowed the bitter powder in applesauce, drifted off into a coma in 10 minutes, and quietly ceased breathing two hours later. His son called me afterwards to let me know, and when I hung up the phone my eyes clouded with tears for the intense beauty and import of this moment.

A month later, my own father died of brain cancer on a different continent, in a hospital because there is no palliative or hospice care where he lived. He was given high-flow oxygen and intravenous fluids when he had pneumonia and was unable to eat or drink in his last few days. I cried many different kinds of tears then, among them tears of frustration because he—and we family members—had so little say in his care over the last days of his life, and his physical suffering was deeper and lasted longer than it needed to.

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50% within the first year after starting HD in patients older than 80 years of age."

Few studies exist comparing the survival benefit of conservative therapy with HD. In the studies that have been performed, the survival benefit appears to dissipate in elderly patients with significant co-morbidities such as ischemic heart disease."

Other studies have found no survival benefit in patients over 80 years or over 70 years with co-morbidities."

Furthermore, initiating HD in patients with poor performance status, who are referred to as "frail," elderly patients with falls, and those with cognitive impairment, may actually be harmful. Patients on HD often have chronic pain significantly more often than the general population, which also affects quality of life.

Conservative therapy may offer a more patient-centered approach, as elderly patients on HD are more likely to be hospitalized and die in the hospital. Patients managed conservatively have a median survival time of 13 to 18 months with fewer hospitalizations and a greater likelihood of dying at home. HD also is unlikely to maintain functional status. In a retrospective study of 3702 nursing home patients who were started on HD, only 13% maintained their functional status at one year. Co-morbidities and baseline disability appear to be the most significant factors that will determine decline.

In fact, conservative therapy actually may be more useful in maintaining or preventing a sharp decline in functional status. Since HD is a therapy that can significantly affect mortality, functional status, and quality of life, it should be considered similarly to chemotherapy when assessing a patient’s fitness for such a burdensome intervention.

As with dementia, many physicians do not have a good understanding of the lack of benefit of HD in many elderly patients, and they may lack the communication skills to guide a patient and family through this difficult decision. This lack of shared decision making may explain why up to 30% of patients older than 75 years withdraw from HD, which suggests that the ability to counsel patients about foregoing HD should be a core competency for any physician who deals with this condition. Patients surveyed often regretted their decision to start HD and reported that they had not had a discussion about end of life care with their physician. National guidelines recommend patients complete advance directives when initiating HD, but few patients accomplish this task, and when they do, it rarely includes stopping HD. Palliative care involvement is likely to be beneficial as a joint palliative care and nephrology program in Australia showed improvement in symptoms and quality of life scores.

Palliative care providers can help patients with AD or elderly patients considering initiating HD. Given the large number of these patients, primary care providers must be comfortable having these challenging discussions incorporating the scientific evidence and patient centered value based themes. Some tips for this type of conversation include the following:

1. Obtain the caregiver’s and patient’s perception of illness;
2. Give relevant data;
3. Elicit concerns and goals based on evidence;
4. Present goals based on patient and caregiver values;
5. Be mindful of prognostic uncertainty;
6. Make a recommendation with permission; and
7. Balance realism and hope.

By utilizing these conversations mindfully and applying the best available evidence, generalists can be more patient centered in their care of these vulnerable patients. Patients and families will be able to make fully informed decisions based on their goals. Along with advance directives, we can ensure that our patients are given the opportunity to determine an appropriate plan for care that respects their wishes and values.

References

* Refer to online edition of article for all references
Embracing Our Role at the End-Of-Life
Sumit Agarwal, Resident Physician

I arrived on the scene to find a big burly nurse, sweat on his brow, performing CPR on my patient—a petite elderly Asian woman. Rhythmic thumps from his compressions filled an otherwise chaotic room.

When CPR stopped and time of death was called, the weight of a thousand rocks caught me unprepared. She was 89; frail, yes, but previously healthy and spry. Just days before her hospitalization for influenza pneumonia, she had been cooking, climbing step ladders to reach spices just out of her grasp. I attempted to make sense of my tears, which were as unexpected as her death. I was riddled by sadness and self-doubt, anxiety and anger. What did I do wrong? Did I miss something on morning rounds? How could I not see this coming? Am I qualified to bear the title ‘physician’?

In the thralls of an uncomfortable confrontation with death, I was singularly obsessed with my failure to save her life. Months of reflection exposed the one-dimensional resolve of my questions as well as the limited philosophy of my training. In a profession that has married itself to finding the elixir of life, proclaiming that preventing death is not our only responsibility as doctors can feel like heresy.

We do not learn this in medical school. We entered the profession to save lives and are trained to be diagnosticians and healers. We spend hours learning about plaque rupture as the pathologic mechanism of heart attacks; what little time that is spent talking about the death that can ensue is reduced to an epidemiologic number meant to be overcome. We spend hours learning about therapies but little time talking about when our therapies fail.

* Refer to online edition of article for all references

SGIM
gressive electrolyte management is inappropriate at the end of life.

Opioid selection requires special consideration in patients who have discontinued dialysis. Fentanyl is considered the safest opioid in ESRD because of its hepatic metabolism and lack of active metabolites, but other opioids can be used safely at end-of-life. Morphine is the opioid of choice in ESRD patients with a prognosis of hours or days given its low cost, widespread availability, and multiple routes of administration including sublingual formulations for patients who cannot swallow. If morphine is used, clinicians should monitor for myoclonus and rotate to another opioid if myoclonus develops. Prolonged administration of morphine in renal failure can lead to delirium and seizures.

All patients who discontinue dialysis are eligible for hospice, so hospice should be recommended concurrent with cessation of dialysis. ESRD patients who receive hospice services are three times less likely to die in the hospital than patients who do not receive hospice. End-of-life care costs are also significantly lower for ESRD patients who receive hospice. Despite these benefits, only 25% of Medicare beneficiaries who died with ESRD in 2012 were enrolled in hospice.

Several studies have examined dialysis discontinuation from the perspective of bereaved family members. One prospective cohort study followed 131 family members longitudinally after dialysis discontinuation of a loved one. In post-death interviews, these family members rated 38% of deaths as “very good” and 47% of deaths as “good.” Another study found low levels of family distress five years after dialysis withdrawal and death of a loved one. These studies suggest that families successfully adapt to the loss of a loved one after discontinuation of dialysis.

MK undergoes radiation and hormonal therapy for his prostate cancer, but his cancer progresses. He is dependent in all activities of daily living, and his bone pain requires increasing doses of opioids. Dialysis becomes difficult, and MK begins to express interest in comfort-focused care. After multiple conversations with his internist and his oncologist, MK decides to stop dialysis and enroll in hospice. His family is supportive. MK dies peacefully at home 9 days later.

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Medical research has long enshrined reduction in mortality and increase in survival as “hard” outcomes—reliable and objective. Beta-blockers unequivocally reduce mortality from systolic heart failure; bevacizumab extends life in individuals with several types of late-stage cancer. This hardened and singular focus on life is mirrored by our unwillingness to talk about death. It is no wonder then that when patients must confront their own mortality, we are uncomfortable and unprepared to help them.

Surveys show that nearly half of physicians, including resident physicians, are uncomfortable talking about death with their patients. This comes as no surprise since academic medical centers are devoid of such training. The result? We avoid the topic altogether. In contrast, we spend orders of magnitude more time being trained in resuscitation to bring patients back to life, getting certified every two years. I have received more feedback on the quality of my compressions than on the family meetings I have led. For physicians who are used to having and providing definitive answers, uncertainty around death and prognosis engenders a system in which we tip-toe around the subject with our patients.

But the tide is turning. There is a growing body of literature that is bucking this trend. Atul Gawande, in *Being Mortal*, explores the aging and dying process, advocating for a way that humanizes it, as opposed to our current practice of over-medicalizing it. In his memoir, *In Breath Becomes Air*, Paul Kalanithi, a resident neurosurgeon-turned-patient, struggles with his own mortality after being diagnosed with stage IV lung cancer at the age of just thirty-six. Both books are best sellers, underscore the burgeoning importance of confronting how we care for those at their final days or weeks of life.

Our role as end-of-life counselors has also crept into our medical journals. One survey of doctors revealed that we physicians, uniquely witness to the harmful effects of invasive measures, would choose do-not-resuscitate for ourselves. We owe it to our patients to bridge the gap in this information asymmetry. After all, we strongly influence how our patients spend the final days of their life. Patients who have end-of-life discussions with their physicians earlier rather than later are less likely to pursue aggressive care in their final days.

While we should continue to increase the accessibility and availability of palliative care, it is too easy to delegate these responsibilities to geriatricians and palliative care specialists. We do our patients a grave disservice by doing so. This is a skill that every physician—surgeons, specialists, intensivists, hospitalists, and primary care physicians—ought to develop, beginning in medical school and residency and then honed throughout our careers. In fact, recognizing its importance, the Hartford Foundation and the Institute of Medicine have commissioned groups to examine the dying process; Medicare has begun reimbursing physicians for having these discussions with their patients; and more states are recognizing and implementing programs around Physician Orders for Life-Sustaining Treatment (POLST).

We cause unbearable amounts of suffering by inserting tubes and lines into every body orifice, surrendering only when the rib-crushing blow of compressions forces us to yield. Surely, we need to recalibrate. End-of-life care should be just as ingrained in our ethos as CPR. My competence as a physician is measured not only by how well I ward off death in some but also how well I ease difficult transitions for others, whether it is a patient who decides to focus on comfort or a family who loses their loved one. With an aging population, we must learn to nimbly navigate this rocky terrain between controlling destiny and accepting destiny so we can better embrace the discomfort at the end-of-life with our patients and for our patients.