

Living Well in the Dying Light

Talking with patients about what's important to them is the key to palliative care.

Interview by Karen McCally '02 (PhD)

How can clinicians best care for patients nearing the end of life? Sally Norton is the inaugural Independence Chair in Nursing and Palliative Care. A faculty member at the School of Nursing since 2001, Norton has secondary appointments in the Departments of Family Medicine and Medical Humanities at the School of Medicine and Dentistry.

When and how should clinicians start an end-of-life conversation?

Some people think it's never too early to start these conversations. For clinicians, I think it's when somebody has a serious progressive illness and the treatments that are available become increasingly burdensome, to the point where the burdens may begin to outweigh any benefits.

Some people will want to continue treatments that may have even a little bit of benefit, and they'll tolerate a lot of burden. Other people may say, "I don't want all this burdensome treatment that makes me feel terrible. I would rather have a shorter amount of time where I feel better." The opportunity to make that choice is predicated on thoughtful and informed conversations.

When the conversation begins, it's essential first to try to find out what the patient understands about what's going on now. Clinicians have to strike a fine balance between spending a lot of time talking in their comfort zone, which is their area of expertise, and checking in with the patient and family about what they understand. We can think that

we're communicating really well, but not really have the other half of that equation. If you leap right in to your own understanding of what patients might need, it can be really far off the mark.

What's the role of the palliative care clinician?

Palliative care clinicians focus on what's most important to you: what symptoms bother you the most; how can we help improve the quality of your life; and what would quality of life look like for you? Patients who receive palliative care may still receive active treatment to prolong life. One thing palliative care clinicians might do is help people establish goals for care. Or reestablish

help the patient to see "Here are the outcomes that are clinically feasible, given where you are now." Often that means: what's important to them, what treatments are available, what are the side effects? And what are their goals? Do they have short-term timelines that they really want to meet, that they would tolerate some pretty high-burden, low-efficacy treatments for? Or not?

What's the state of quality and access to palliative care?

Right now there's a lot of variation nationally. Every patient deserves the best care we can provide. We've made tremendous progress recently through a project called Measuring What Mat-

palliative care. Those standards are rolling out now. Rochester is really an epicenter of research and clinical practice in palliative care. Right now, we're implementing palliative care teams in nursing homes, trying to figure out what helps it be successful and what barriers get in the way. We're doing amazing work in communication. We have an incredible web of investigators and clinicians who work together quite well.

We think of best-case scenarios in terms of cures. What's a best-case scenario for a palliative care patient?

The best case scenario is that people receive the best treatment to provide the highest quality of life possible. I've seen people who didn't want to live any longer get wonderful treatment of their pains and symptoms. All of a sudden, they start making different choices. They might start eating. You see the world differently when your symptoms are addressed.

Some of the earliest successes are in Oregon, where I did my postdoc. Partly, it was because they passed the Death With Dignity Act. It caused clinicians to say, "We don't want people to choose to end their own lives because we're not doing a good job managing their symptoms." So you saw a real shift in Oregon toward some of the most progressive palliative care in the nation. There was an increase in the percentage of patients who died at home, who died with home hospice, and a tremendous decrease in deaths in the hospital among certain subpopulations. And a miniscule number of people who actually went through with the Death With Dignity assisted suicide protocol.



COMMUNICATOR: Norton cochairs a national task force to identify quality measures to improve practices in palliative care.

goals for care if the conditions change. Sometimes people have this idea that they're going to do this treatment, and their goal is it will cure their disease. When it becomes increasingly clear that the treatment isn't going to cure the disease, then the clinician has to help the patient understand that they aren't going to get the outcome they'd hoped for. So they

ters, which I cochair. It's a joint task force between the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association. We've identified a set of quality measures that are meaningful to patients and families, and that will allow us to benchmark, evaluate, and improve our practices across all settings that deliver