A Conversation with Dr. Ann Berger on Palliative Care at NIH

Dr. Ann Berger is chief of the NIH Clinical Center’s Pain and Palliative Care Service (PPCS), which she founded in 2000. The PPCS functions as a consult service for clinical teams and patients who are enrolled in clinical trials at the NIH hospital in Bethesda. More than half of the patients seen by Dr. Berger and her team have cancer and are enrolled in NCI-sponsored clinical trials. Dr. Berger has written extensively about pain management and palliative care, including a book for the lay audience, Healing Pain: The Innovative, Breakthrough Plan to Overcome Your Physical Pain and Emotional Suffering, published by Rodale Books in 2006.

How does the PPCS function within the NIH Clinical Center?

Dr. Berger

Our core team consists of two nurse practitioners, three full-time attending physicians, an administrative coordinator, and me. We assess patients and decide who will benefit them the most from the larger interdisciplinary team, which includes members of the spiritual ministry, social workers, recreational therapists, dieticians, pharmacists, rehabilitative medicine practitioners, psychiatrists, and also those who work in complementary modalities, such as acupuncture, pet and art therapy, massage therapy, hypnosis, and energy work in the form of Reiki. We see this interdisciplinary collection of skills as part of our overall tool box, along with medications.

We usually work with patients over a long period of time, because we believe that they should be followed across the trajectory of their disease. So, for example, if a person is enrolled in a bone marrow transplant clinical trial, we see them on day one, along with their transplant team, during a meet-and-greet session. We do a palliative care assessment to get a sense of their baseline physical, psychological, and social status—how they are and how they tick, essentially—so that when they start to go through the process, we can help them more effectively. We’re with them for their transplants; the radiation; the nausea and vomiting and mucositis; the graft-versus-host disease (GvHD). We come with balloons and parties and we sing and dance, when appropriate, and we’re also there for end-of-life care, if that happens. We also get to know the family members of patients and their psychosocial and spiritual issues, which can make end-of-life care a lot easier for everyone concerned, including the staff.

For patients who have died, we hold a memorial service every year and invite staff to attend. And we conduct bereavement follow-up care for the family members at 2 months, 6 months, 9 months, and 1 year.

This sounds like a lot of work for such a small team. How do you manage to do it?

Dr. Berger

We have a team of volunteers who help us, and we just move. I’ve seen health care from many different angles. I have a master’s degree in oncology nursing, I’m a physician, and I’m also a breast cancer survivor. I had bilateral mastectomies and I’ve also had heart surgery, both times while my children were still young. I can put myself in these patients’ shoes because I have been in their shoes. So it’s easy, and we just do it.

Do you have your own research protocols?

Dr. Berger

We function mostly as a clinical service, but we also do research because we’re part of a research institution. We ran a pet therapy protocol, for example, and also a hypnosis protocol with sickle cell cancer patients. We had a larger study with the nursing group at the hospital looking at the efficacy of palliative care, where patients were randomized to receive our service or not. We’ve also run protocols with GvHD patients, because we see every one of them at the hospital. So, we usually write up things that are practical in the course of our normal care with patients.

Our biggest current area of study is part of a training program looking at the meaning of healing. We talk about healing a lot in palliative care. We say that patients may not be cured of their illness, but they...
can be healed; that the healing brings them a sense of “wholeness.” But what exactly is this phenomenon? We’ve now interviewed 10 patients who survived cancer and described being healed, in 3-hour in-depth sessions, and we’re analyzing their testimonies. We’re going to speak with patients who have survived cardiac conditions, also, to see what the experience of healing meant for them. We want to understand what this is and how people can get there, and then see if there’s a way to quantify the experience so that health care providers can help other patients achieve the same thing.

**What is holding back palliative care around the country, and what can be done about it?**

One simple thing that patients can do is to ask for palliative care, and ask for it early. They can give a list of their symptoms to their health care providers—pain, depression, stress about finances, concerns about their children, for example—and ask, is there a palliative care team here that can help me? Are there people who can help me with my quality of life? These services are becoming more and more available, and if there isn’t an established palliative care service at the institution where a patient is being treated, the American Academy of Hospice and Palliative Medicine maintains a list of practitioners that people can refer to.

The biggest institutional obstacle to palliative care is the struggle between cure and palliation. On the oncology side, many still see palliative care as end-of-life care and not in broader terms. And even in the palliative care community, many still convey themselves as end-of-life caregivers. So, it’s a problem that’s being perpetuated on both sides.

If someone wants to start a palliative care service at a hospital or clinic, they need to begin at the bedside helping one patient at a time, to show everyone what they can do, because many people still don’t know what palliative care is. They need to treat the service that they want to establish as if it were a private practice: be there, be available, and, also, be palliative for other staff members.

**Clinical staff members need palliative care, too?**

The primary unit of palliative care is the patient and family. But much of what we do is also palliative care for staff. It’s very difficult to take care of critically ill patients, particularly those who have cancer. I talk about this when I’m asked to give lectures on burnout. Many of the things that we do for patients can also be done for staff members at the hospital.

It can be very difficult for oncologists to lose patients. And so sometimes we run into struggles when we talk with them about the best balance between aggressive treatment and comforting a patient at the end of life. We as palliative care staff need to be sitting down with the oncologist and asking, “Hey, is this difficult for you right now?” Everybody wants to help the patient. Nobody is trying to do them harm. And there usually isn’t only one right way to do something.

So yes, palliating the staff is something that needs to happen, too, because if you don’t, you’ll just end up fighting and you won’t have a successful team. Our team is very successful. We have 700 new patients each year and 7,000 follow ups a year. We’re the busiest service in the hospital.

—Brittany Moya del Pino