Redefining Palliative Care

Author:

EDITOR’S NOTE This is the second installment from our roundtable with oncology nursing experts discussing some of the key challenges in oncology nursing today. Part 1, on symptom management, appeared in our August issue. For video highlights from our Oncology Nursing News roundtable, click here

Helen C. Foley (segment moderator): Palliative care is an essential component of good oncology care. In most institutions, considerable efforts are being undertaken to improve this care for our patients. How has palliative care changed in recent years, and what are some of the key issues and challenges nurses today face in providing this care?

Ruth McCorkle: Palliative care still sometimes has a bad name. For years, the public and physicians have really associated it with end-of-life and hospice care. Now, the Institute of Medicine and others have redefined palliative care in terms of a symptom management approach—helping people from the time of diagnosis through to recovery and cure, rather than just through the progression of a disease. Changing the mindset is not easy. At the University of Texas MD Anderson Cancer Center, for example, palliative care is called supportive care. We need a way to expand the concept to include keeping patients comfortable at diagnosis and understanding that comfort means really improving someone’s quality of life.

Foley: We already have palliative care as part of the treatment plan, from diagnosis through treatment. Even into survivorship, palliative care has a big role, doesn’t it?
Janine Overcash: Palliative care happens in many arenas, from the home to inpatient care, and it involves chemotherapies and radiation therapies to reduce pain. We are now redefining all of the tools to combat pain and provide comfort to patients. As we develop a larger arsenal of options, we will continue to see palliative care reshaped. We, as nurses, not only help to provide this care but also can help to educate families, other nurses, and nursing students regarding palliation.

Foley: Do you think that patients and families have a certain mindset about palliative care?

Overcash: This can be folded into the notion of hospice, a concept that families aren’t ready for. We have to educate our patients and families that palliative care has changed. It isn’t about end of life. It is about comfort. It is about doing things as we’ve just been suggesting, proactively, to help ward off unpleasant symptoms. This is a changing dimension of science and of care.

Barbara Given: There is still a disconnect that contributes to families and others feeling both weary and wary of what is going on. When the oncologist says that palliative care or supportive care—whatever the word they use—is going to happen, that the patient doesn’t have to come back now for a few months, the family feels left alone, because whatever they have gone through for 1, 2, or 3 years of care in that setting is now over. Families are worried about that disconnect and feel there is a certain message when they don’t need to come back anymore. Family members who don’t understand or aren’t assertive enough to say, “I want some connection here,” or when no one checks them for 2 months, this can add to their loneliness and loss of security.

Kronk: That is where we really need to involve a multidisciplinary team that includes a visiting nurse or a social worker. Palliative care presents an important opportunity to involve other team members.

Foley: Early and often, I would say, too. That is one of our problems. We wait so long to introduce the idea of palliative care.

Given: I also think the whole payment mechanism interferes with the smooth transition in families’ understanding. When half of the first discussion or the second discussion is about payment, it is really very traumatic for a family now believing this is the end or close to the end.

Foley: That leads in to our next question: What needs to be done to improve palliative care options?
McCorkle: One of the really important initiatives is out of the Robert Wood Johnson Foundation, which has supported this area, under the guidance of Diane Meier, MD, and Sean Morrison, MD. [More information on The Center to Advance Palliative Care can be found at www.capc.org].

From a nursing perspective, if you look at the hospice movement, there are national or world movements driven by physicians. The public still sees the physician as the captain and the individual in charge. As nurses become more comfortable and knowledgeable, along with a shortage of physicians, the public will begin to understand that nurses have these skills. There are now initiatives in place to make palliative care available to patients, acknowledging that it’s their right to have this care. There is going to have to be a major campaign by physicians and other healthcare professionals, and that is a good thing. We are not going to take your patient away from you; we are going to work collaboratively. There is enough for everybody to do.

Foley: Perhaps the best thing that has happened in the last few years is the research which demonstrated that patients can actually live longer if they get palliative care from the point of diagnosis. Again, early and often. Our physician colleagues are now seeing the real benefit of palliative care as part of the treatment plan, which is fantastic.

McCorkle: The interesting thing about this is that we also have nurse research demonstrating these same results. It just doesn’t get the same kind of publicity. We have demonstrated that we have good outcomes to show that nurses helping patients to manage their symptoms and coordinating their care can make a tremendous difference.

Foley: Improving the quality of life not only for the patient, but for the family.

Overcash: We can do this at big academic medical centers or in urban areas, but a lot of our patients are out in small rural areas where options through palliative care agencies may be more limited. We have a long way to go to continue to serve our patients in palliative care throughout our nation and throughout various communities.