QUESTION

How is hope reimagined at the end of life?

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While working as a women’s health nurse practitioner (NP) in the obstetric and gynecologic setting for 10 years, I found life circumstances steering my family and I to relocate. An opportunity arose for me to change gears and enter the world of women’s health oncology. After seven months in my new role as a gynecologic oncology NP, I found myself sitting in a family meeting. The meeting involved myself, representing my clinical colleagues, along with team members from palliative care and social work. The patient was in her 80s with a diagnosis of recurrent endometrial cancer. Her health history included multiple previous surgeries and chemotherapy, and, unfortunately, she was no longer a safe candidate for treatment. She had comorbidities and chronic sequelae from past treatments.

I realized my role in advance, which included reiterating to the family that additional treatment would no longer be an option. My colleagues felt confident that this message had already been delivered and would, therefore, not come as a surprise. However, when it came time for me to speak about the next steps, the reaction of the family was one of shock and despair. It was uncomfortable for myself and the patient’s family members. After a good deal of sharing, listening, and painful silence, a plan to refer to hospice was made. The patient and her family members agreed with how to proceed. I left this meeting feeling relieved that the patient and family were going to receive the care and support that they needed. But, I also left with questions. “How could this patient and family be unaware of what our clinical team had been communicating? What were we doing wrong that was resulting in this communication failure?”

Hope is powerful and has been proven to affect health and outcomes in this patient population in a positive manner. The issue is how to bring up an end-of-life scenario to a patient and not crush his or her hope? In oncology, we often change the plan of care from hope for a cure to optimizing the patient’s remaining weeks or months without properly preparing the patient and family. There has to be a way to improve this communication.

The timing of when the concept of hospice is initially discussed during a patient’s cancer journey varies across practices. Some practice uniformity may lend a great deal to the appropriate and timely utilization of hospice. Perhaps the time to start talking about hospice is during initial conversations about the cancer diagnosis, even if the patient may never need hospice care. Educating patients and their loved ones during the initial diagnosis is a more reasonable approach. Creating a standardized national guideline for practice could also help. Patients and their families may have misconceptions about hospice. Early discussions about hospice can help offset the misconceptions about this invaluable resource.

No one wants to inadvertently or otherwise eliminate hope, one of the most important coping mechanisms for patients. However, longer and more frequent conversations may help all involved get to a place of less fear and hesitation. Sharing that hospice does not equate to automatic loss of life within a short period of time could provide clarity for the patient. Providers are busy and workloads are full, which limits time for discussions. Still, if patients are not receptive at first, subsequent discussions about hospice may lead to timely and appropriate referrals.

To be clear, I know that providers are constantly striving to keep their patients going in the right direction. I also know that patients and their loved ones are trying their best to be positive, to keep hope alive, and to be supportive. My intent in writing this is to keep the conversation going about how to clear the hurdles of appropriate and timely hospice referrals.

Ultimately, hope can be reimagined to serve the patient and his or her family members in the patient’s last season of life. As providers, it is our job to reimagine how we get them there.

RESOURCES

- The Conversation Project
  A help guide with patient discussions about end-of-life care options
  www.aafp.org/patient-care/inform/conversation-project.html

- Difficult Conversations: Dealing With the Spiritual Needs of Patients With Cancer
  Oncology Nursing News article that examines the link between spirituality and end-of-life care

- What Matters Now
  Free personal websites for people facing serious illness
  www.whatmattersnow.org

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