

# To Live Until You Die: Quality of Life at the End of Life

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Oncology nurses are expected to be knowledgeable in dealing with palliative care and end-of-life issues. However, patients with advanced cancer often are not offered palliative care until they are approaching the very end of their lives. Oncology nurses need to step up as patient advocates. They need to educate patients, families, physicians, and the public that aggressive cancer care can coexist with aggressive palliative care. This article discusses how to introduce palliative care much earlier in the cancer experience. Oncology nurses can become empowered and then help other nurses to improve quality of life for their patients with advanced cancer as they approach the end of their lives.

**W**e don't know how to do this. . . . We've never done this before," said the sister of an actively dying patient whom I had been called to see in one of our intensive care units. The staff wanted me to talk with the family of this woman who was "too young to die."

We are so used to our world of alarms, sterile environments, windows that don't open, fluorescent lights, indecipherable words, high-tech equipment, and multiple professionals going about their daily business of health care. We forget that most of our patients and families have *never done this before*. Many have never even stepped inside the door of a hospital before, have never been really sick, have never experienced real pain and suffering. This is a foreign world, and they wish that they had never gotten a ticket to ride on this cancer train. And who better to be the guide/confidante/advocate/train conductor than the oncology nurse?

Dame Cicely Saunders, the founder of the modern hospice movement, wrote, "You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but to live until you die" (Twycross, n.d.). This has become the unofficial motto of hospices around the world: "To live until you die." That's the thing that so many people don't get. It's all about life—not death! How many times have people asked you, "How can you be an oncology nurse?" Hospice nurses get the same question. But some of the most awesome nurses—who really and truly like what they do—are hospice and oncology nurses. So, what's the secret? Why do you do what you do? Isn't it depressing? Isn't it sad?

## The Secret Is Hope

"Hope?" you may ask. "How can you have hope?" Well, hope is a very fluid thing. It changes depending on where you are on the trajectory of life. For newly diagnosed patients with cancer,

### At a Glance

- ◆ Oncology nurses have an opportunity to help patients with advanced cancer explore their options by facilitating difficult conversations.
- ◆ Hope is always present—just in different forms.
- ◆ Oncology nurses make a difference as educators, as advocates, and with their presence.

the hope is for a cure. If that is a realistic hope, then we are their "cheerleaders." We are there to help them make it through all the tough treatments that we have to throw at them. We are there to manage their symptoms to the best of our abilities so they can "stay the course." With more advanced cancers, the hope may be for control. That is a very real hope, as we've already seen how Gleevec® (imatinib mesylate, Novartis Oncology) paved the way for patients with chronic myeloid leukemia. Researchers are working furiously, trying to find more ways to turn cancer into the next diabetes. What a concept: living with cancer. But most

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people won't put up with as much if cure is not likely. If insulin made diabetics miserable, a lot fewer patients with diabetes would be taking it daily. And if control is not a possibility, there is always hope for time. Time to finish business, to tell someone "I'm sorry," to leave a legacy, to experience something special like a graduation or a marriage, or maybe even time for that "magic drug" to be invented. The goal is to have interventions that make you feel better—not worse. And finally, there is hope for a "good death." Most nurses have been present for a "bad death." You know the difference; instead of machines, bright lights, surrounded by strangers, pain, and suffering, patients are where they want to be, as comfortable as possible, doing what they want to do, surrounded by the people they love, with their symptoms well managed and their goals accomplished.

## Health Care Is Changing

People used to die at home, surrounded by their families, with their hands held. Now they are dying in institutions, hooked up to machines and surrounded by strangers. The United States has been called a "death-denying society" (National Hospice and Palliative Care Organization, n.d.). Even though this is starting to improve, many of our physicians and nurses never received education about dealing with the end of life. Many feel they have failed when their patients die. Nursing training is not much better but is improving. Aren't we here to cure people? Aren't oncology nurses and physicians trying to cure cancer? If we didn't "push the envelope," we wouldn't have gotten as far as we are today. And we've come a long way. There are more cancer "survivors" than ever before. Every day, we hear about a new discovery, a new theory, a new intervention. We are aggressively fighting the "war on cancer."

I work in a large teaching hospital that does some very awesome things. We are known for aggressively fighting for our patients' lives. But isn't part of caring for people to actually "care" for them? Doesn't our role include helping them when we can't "kiss it and make it all better" like mom used to do?

Unfortunately, the public gets the majority of their health information from television (Adams & Snedden, 2006). I'm not talking about documentaries. I'm talking about shows such as "House" and "HawthoRNe." How many top nursing administrators do you know who regularly work at the bedside—on all shifts? How many teams of premier physicians do you know who can spend days and hours on one patient? When I'm teaching the public, I often tell them that there is a reason that we still call it "practicing medicine"—because we are still learning. Much of what we do is guesswork. We may have some highly educated and talented "guessers," but it's far from perfect.

Predicting prognosis is one of those difficult things that we can only "guestimate" (Glare et al., 2003). If there was a neat little algorithm to make this prediction, it would be easy. Although we have a growing number of tools that can help us guess better (End of Life/Palliative Education Resource Center, 2004; Finlay & Casarett, 2009; Lau, 2009; Victoria Hospice Society, 2001), it is still a guess. We must remember that for every 95% survival rate, 5% did not survive. Likewise, for every 5% chance of survival, someone was in that 5%.

Unfortunately, there are just some things man cannot cure—yet. We know that stage IV cancers are considered to be terminal cancers. Do some people survive? Yes, but very few. We also know that all cancers are not alike. For example, a patient with stage I breast cancer has a better prognosis than a patient with the rarely found stage I pancreatic cancer. As oncology nurses, you know these things. Don't you regularly have family, friends, and coworkers asking your opinions about the cancers they or their loved ones have been diagnosed with? They are aware that you know much more than they do. You have an opportunity here to educate, to advocate, to help people with those difficult conversations, exploring what their goals are if things don't go well.

## The Big Questions

- What if things don't go well, how aggressive do you want your doctors and nurses to be?
- What if you can no longer speak for yourself, who do you want to speak for you?
- How did you decide to pick your surrogate? Maybe it should not be the person who loves you the most—he or she may not be able to let you go if that is your choice.
- Have you talked about your thoughts about this with your clinicians, your surrogate, and your family?
- Do you have an advance directive? Have you made copies of your advance directive, and do you and your loved ones know where they are?

As a nurse, you have to be flexible enough to support decisions that may be different from what yours would be—and allow the decisions to change with time. When people are faced with the end of life, decisions may become different from what we thought they would be. If goals of care are discussed early in a patient's healthcare experience, such difficult conversations become less difficult. Prepare for the worst, but hope for the best. This conversation can be revisited periodically.

## What Is Quality of Life?

According to the World Health Organization (2009), palliative care is for anyone with a life-threatening illness. But focusing on quality of life is the key to it all. This is what palliative care is all about: providing good symptom management (i.e., supportive care), being able to have difficult conversations, being "present," and championing quality of life.

## Symptom Management

We have made great strides in controlling pain, nausea, dyspnea, and other symptoms encountered by patients with cancer. Oncology nurses should be experts on a variety of supportive care tools (both drug and non-drug) that can make the quality of our patients' lives the best it can be. Why do you think patients have championed physician-assisted suicide? It's not the fear of death; it's the fear of dying—what you must go through before you die. "I'm not afraid at all of dying, but I'm terrified of what waits for me between here and there" (L. Cothron, personal communication, July 24, 2009).

## Difficult Conversations

How can our patients make informed decisions about what they do and do not want if nobody talks about prognosis, all of the options, and patient goals? Without advance directives and healthcare surrogates, who will speak for our patients when they can no longer speak for themselves?

In a prospective, longitudinal, multisite cohort study of 332 patient and caregiver dyads that was funded by the National Cancer Institute, patients who were able to have end-of-life discussions clarifying their goals and care expectations had significantly less aggressive interventions in their final days (Barclay, 2008). The study also linked aggressive care with poorer quality of life and increased caregiver depression, whereas longer hospice stays were linked with better patient and caregiver quality of life.

Most physicians do not have the time to have one- or two-hour family conferences plus other extended conversations with each patient. But palliative care physicians excel at this. Oncology nurses can be the intermediary to facilitate such conversations and open the door to referrals. They can educate other clinicians as well as their patients and their patients' families about what palliative care has to offer.

## Presence

Isn't that also part of being a nurse? Isn't that what nursing "care" is all about? Sometimes just "being there" is the most important thing we can do. We call it "the power of presence." You don't have to have any "right words" or "things" you can do for your patients—just being there to witness, to hold a hand, to show that you care—can be as powerful as any high-tech intervention we can offer.

## Quality of Life

In 1991, Betty Ferrell developed her Quality of Life Model, which was based on Dame Cicely's philosophy (Ferrell, Grant, Padilla, Vemuri, & Rhiner, 1991). It looks at the whole person: physical, psychological, spiritual, and emotional well-being. All are considered to be equally important. In this world of specialists and disjointed care, the nurse is the person looking at the whole patient. Who better to be an advocate for quality of life through good palliative care than the oncology nurse?

## Communication Is Key

In health care, we belong to a special club with our own special language. Did you have any idea what "I&O" was before you became a nurse? Did you ever use the word void for urinating? We have become so comfortable in our environment that we can forget how truly frightening it all is for lay persons. Communication is everything. Remember when "cancer victims" changed to "cancer survivors?" Think about what a dramatic difference that made. We need to look at the words we are using at the end of life, too (see Figure 1).

And listen to patients' words: "Doc, I want you to do everything!" Do they know what "everything" is? Just because we can

do something—does that mean we have to do it? These aren't easy questions with easy answers. That's what makes ethics so hard. There are no absolutes and no obvious right or wrong answers. That's why we call them difficult conversations.

## Oncology Nurses as Teachers

At Tampa General Hospital, I started a Palliative Care Resource Nurse (PCRN) and Palliative Care Resource Professional (PCRP) Program in 2005. PCRN and PCRP (who are non-nurse healthcare professionals) attend a 25-contact-hour End-of-Life Nursing Education Consortium (ELNEC) Training Program. They also become ELNEC trainers through the American Association of Critical-Care Nurses. They are tasked with being resources at the end of life. They advocate for their patients and educate them along with their families, physicians, and other clinicians. We now have more than 400 PCRN and PCRP at our facility (including oncology nurses, nononcology nurses, and other healthcare professionals). We have expanded this concept to other hospitals as well as nonhospital settings. Oncology nurses, by virtue of their training, knowledge, and mission, should be a critical component in promoting this concept. But what about all of those patients with cancer who are not seeing oncology nurses? We have a duty to reach out to them, too.

My Oncology Nursing Society (ONS) chapter, the Nature Coast Nurses Chapter of ONS, encourages nononcology nurses to come to our educational programs. They can buy an "annual subscription" allowing them to attend all regularly scheduled programs. They are not ONS members and do not receive the benefits of ONS membership. But we have brought a number of nurses into oncology and ONS after they got involved with our chapter. We offer 22 educational programs each year and have presented an ELNEC Oncology Conference, with several of the attendees continuing on to become PCRN in their communities. These are things that you can do, too. As oncology nurses, you make a difference every day.

**Instead of:** We are going to withdraw treatment. (You're going to ignore her?)

**Say:** Sometimes the burdens of these interventions outweigh the benefits.

**Instead of:** There is nothing more we can do. (You aren't going to do anything for her now?)

**Say:** There is much we can do to keep your mom comfortable. We will be there for her and you!

**Instead of:** What do you want us to do? (Me? What do I know? You went to school for this!)

**Say:** Some things man cannot cure. The outcome to this is not in our control.

**Instead of:** Do you want to turn off the machines? (You mean, do you want me to kill my mom?)

**Say:** Did your mom ever talk about what she would want in this situation? Would you like us to allow your mom to die naturally?

### Figure 1. Choosing Your Words Wisely When Having Difficult Conversations

I wrote the following poem for oncology nurses—because of who you are and what you do. (Sing this to the tune of “The Rose” by Amanda McBroom [n.d.], sung by Bette Midler in the film of the same name.)

### “My Nurse”

When the night is dark and endless  
And I’m feeling all alone  
Sickness makes me feel so friendless  
Or that I need to atone.

But then someone sits beside me  
And she starts to lift the curse  
Rubs my back and talks so softly  
She’s my lifeline—she’s my nurse.

When my husband’s slowly dying  
60 years is not enough  
I stand strong—I’m really trying  
But it’s getting—oh so tough.

Then he tells me that it’s over  
That the pain will get no worse  
While I cry on his strong shoulder  
I thank God—that he’s my nurse.

Nurses work in many places  
Every hour of the day  
And they leave so many traces  
In what they do and what they say  
We forget that simple actions  
Whether friendly or quite terse  
Elicit long-lasting reactions  
You leave a mark—when you’re a nurse.

Sometimes technical, sometimes daring  
We see the best, we see the worst  
But our cornerstone is caring  
Why else would you become a nurse?

## Conclusion

Nobody ever says, “I wish I could end my days in an intensive care unit with inadequate symptom management and surrounded by strangers instead of with my loved ones and on my own terms.” In the documentary “Notes From the Edge,” a physician who was dying from cancer told his oncology nurse, “I don’t want to manage my death. I want to manage my life!” (Drazen, 1997). Instead of a negative and horrible memory, this can be the most profound experience that any person will face. This includes the patient, his or her loved ones, and clinicians. Your patient’s loved ones will remember you for the rest of their lives because you helped make it better than it could have been.

Oncology nurses can make the difference by sharing their specialized knowledge with their patients, their families, their coworkers, nononcology nurses, and the public. They make a difference every day as educators, as advocates, and simply by their presence. What better reason is there for becoming a nurse?

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