

# THE TOTAL PATIENT

## Where to die: The impact of setting on quality of life for patients and caregivers

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As this article was being written, we learned of the death of Elizabeth Edwards on December 7, 2010. She was advised that further treatment to control her cancer would be “unproductive,” but she continued with hospice services to control her symptoms. She chose to die at home surrounded by loved ones. In an insightful article, “Dying at home, surrounded by family,” CNNhealth.com writer/producer Madison Park wrote,

“Next to picking a life partner or becoming a parent, there isn’t a more personal decision than how to die for those who get the opportunity to choose.... it’s a heavy consideration for terminally ill patients. For some, making the conscious decision to end treatment is tantamount to giving up or giving in. They worry about disappointing the people who care about them.”<sup>1</sup>

Ms. Park writes that more patients are choosing to die at home with hospice services so they can be made comfortable among loved ones in familiar surroundings. In her article, she quoted Dr. David Casarett, associate professor of medicine at the University of Pennsylvania:

“People in hospice want to use whatever time they have to live the best

way they can. I don’t think it’s giving up. It’s making a careful choice. The easiest thing is to go after treatment after treatment, and say yes to whatever gets offered next. The bravest thing is asking yourself what’s important, who’s important, what’s best for you and your family and choosing hospice that way.”<sup>1</sup>

The American Cancer Society (ACS) also reflected on the message sent by the death of Mrs. Edwards. In an official response, Otis Brawley, MD, ACS Chief Medical Officer, said:

“The courage, grace, and dignity that Mrs. Edwards has shown us as she faced her cancer journey is extraordinary. She has been and will continue to be an inspiration to patients, their families, and to the health care professionals who care for cancer patients.

“The way she faced the end of her life also serves as an example to us all. Many patients are hesitant to accept hospice and supportive care, despite the fact that for many cancer patients supportive care is more likely to lead to a better quality and longer quantity of life than aggressive therapy.

“We can be grateful to Mrs. Edwards. Her decisions and open discussion of them bring an awareness that is good for all of us. Her presence will be missed, but her impact will live on forever.”<sup>2</sup>

### HOSPITAL SETTING IS MORE STRESSFUL

The location in which a cancer patient dies has an impact on his or her quality of life (QOL) at the end-of-life stage. According to a prospective, longitudinal study by researchers at Dana-Farber Cancer Institute in Boston, Massachusetts, when a cancer patient dies in a hospital room or in an ICU, the quality of life is far worse than it is for the patient who dies at home with hospice services. This research led to an additional unexpected finding: caregivers are at greater risk for developing psychiatric illness if the patient dies in the hospital or in an ICU instead of at home.

Results of this study by Alexi Wright, MD, Holly Prigerson, PhD, and co-authors were recently published in the *Journal of Clinical Oncology*.<sup>3</sup> Seven cancer centers participated in the project, which was coordinated by Dr. Prigerson, director of Dana-Farber’s Center for Psycho-Oncology & Palliative Care Research. In the study, which recruited participants from 2002 to 2008, 342 patients with advanced cancer and their caregivers were followed until the patients died, a period that averaged 4.5 months.

The researchers first interviewed the patients and their caregivers, usually family members, when they entered the study. The caregiver’s mental health

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was evaluated at the onset of the study to uncover any pre-existing psychiatric conditions. The researchers then met with the caregiver again within 2 weeks after the patient's death for an assessment of the patient's quality of life and the amount of physical and psychological stress experienced during the last week of life. In situations where there was more than one caregiver, the investigators interviewed the person who was most closely involved with caring for the patient during that last week. Six months later the researchers again met with the caregiver to evaluate the patient's last week of life. However, in addition to assessing the patient's mental health, the investigators also re-evaluated the caregiver's mental health.

#### **IMPACT ON CAREGIVERS' MENTAL HEALTH**

Patients who died at home with hospice services experienced a better quality of life and less physical and emotional distress than those who died in an ICU or in the hospital. The ICU was a particularly devastating location for caregivers and patients alike. Posttraumatic stress disorder (PTSD) was diagnosed five times more frequently in caregivers of patients who died in an ICU than in caregivers of patients who died at home. The

authors report that their study is the first to show that caregivers of patients who die in the ICU are at a greater risk for developing PTSD.

Death in the hospital but not in an ICU also led to problems among families and other loved ones. These caregivers were more likely to develop prolonged grief disorder (PGD), which the investigators describe as "an intense and disabling form of grief which lasts more than six months."<sup>3</sup>

#### **WHEN CHOICE IS NOT AN OPTION**

Wright and coauthors wrote that despite the fact that most patients who are dying of cancer would like to spend their end-of-life days at home, 36% die in a hospital and 8% die in an ICU, where they may experience painful invasive procedures. Thus in contrast to home or hospice care that emphasizes relieving pain and encourages the patient to die in a peaceful environment, ICU care can be traumatic not only for patients, but also for their families and caregivers. Dr. Wright explained, "In the ICU and in the hospital, we're trying to do everything we can to prolong people's lives at the very end of their life. At home, there's much more attention and focus on really addressing the symptoms patients have ... probably a more holistic approach." She cautions relatives and caregivers,

"You may be at significantly higher risk for developing psychiatric disorders after losing someone in the ICU. And you should know to seek help if you're experiencing disabling symptoms of grief or anxiety; that this may be because of what you witnessed at the end of your loved one's life and not just a normal part of grieving."<sup>4</sup> ■

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