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## FROM THE EDITOR

# When is dying?

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Death is doubtless the exhaustion of all desire, including that of dying. It's only from life, from the knowledge of life, that one can have the desire to die. Such a death wish is still a reflex of life.

Jorge Semprun (1997)

O G-d, inform me of my end! What is the measure of my days?  
Psalms, 39:5

Some time ago I was asked to see a young woman, Jan. She was in her late 30s, married, with teenage children. Jan had widely metastatic melanoma. The palliative care team was invited to manage her pain and bowel obstruction. We thought she had at most a few weeks to live. I approached her medical oncologist to arrange an early discharge so that Jan could spend her last few weeks of life with family. The oncologist agreed that she was dying but thought she could benefit from more chemotherapy. I was flummoxed. What was his understanding of dying when it included chemotherapy? What did I understand by the word “dying”? Should it include life-prolonging “palliative” chemotherapy? What does chemotherapy mean to a “dying” patient?

It is important to have a clear understanding of the practical use and meaning of the word “dying.” It is equally important that different disciplines within oncology speak the same language. Patients can be traumatized by roller-coaster rides where hopes are built and crushed contemporaneously.

When is dying? A common response is that we are dying from the day we are born. Each of us is dying now. Our telomeres are shortening, the hourglass is emptying of sand. So how is this different from a patient with incurable cancer who is “really” dying? Asked differently, when is living dying? *The Pawnbroker* captured this sentiment in a discussion between relatives and the doctor: “Some world we live in, isn't it? Well, then. I can eliminate my bedside diplomacy, Mrs. Rubin, your father is dying.” “Who isn't, Doctor?” Sol said. “The question is, how close is he to death?” (Wallant, 1961).

To a 40-year-old woman with breast cancer and stable metastatic bone disease, whose survival can be measured in years, do we say to her, “Your disease is incurable, you are dying”? Or a 35-year-old man with widely metastatic osteosarcoma who, when given bad news, responded “I am dying.” When asked what he understood by dying, he replied, “within 5 years . . . I am not 40 yet.” What of a 20-year-old man with pneumonia and septic shock? He will die if untreated. Is this concept one of “reversible dying”? Could this apply in certain circumstances to chemotherapy and cancer?

Or maybe dying is a reduced mean life expectancy for a certain socioeconomic status in a given society. If so, then is a middle-aged smoker with poorly controlled diabetes, hypertension, and heart disease properly labeled as “dying”? How do we progress this discussion?

In 2005 Israel passed legislation, the “Dying Patient Act,” as a response to the changes in medicine, technology, and medical culture over the past few decades. Issues such as nutrition at the end of life, euthanasia, when to “pull the plug” and surrogacy are addressed. The legislation—which was prepared by a committee representative of the full spectrum of religious and national persuasions—states (paraphrased): A dying person is defined as one who will die within 6 months despite medical therapy; the last 2 weeks of expected life is defined as the final stage (Steinberg & Sprung, 2006).

What is the point of defining dying at 6 months? God's reply to the Psalmist was not sympathetic: “I have decreed that the end of flesh and blood is not knowable” (Babylonian Talmud, Shabbat 30a). Some say God is merciful in denying us foreknowledge of the moment of death. It is a hiatus of ignorance into which we can blissfully deny. The exceptions, those facing execution and those by their own hand, prove the rule.

Christakis and Lamont (2000) showed that in a group of terminally ill patients, doctors were more inaccurate the longer the predicted survival and they were consistently overly optimistic. Three hundred forty-three doctors estimated survival for 468 terminally ill patients. Median survival was 24 days. Only

20% of predictions were accurate (within 33% of actual survival); 63% were optimistic and 17% were pessimistic. Experienced doctors were more accurate in clinical estimates of survival. However accuracy diminished significantly beyond 3 months and diminished the longer the doctor–patient relationship existed.

An alternative point of view might declare: “Never say die.” Given our limitations in predicting the time of death for a given individual and given we can sometimes delay death with treatment, is it not best to treat 99 people (even if in retrospect it is futile) for the sake of 1 patient, whose life will be “saved”?

In fact some people have suggested dispensing with the word “dying” altogether. That is, one is alive until one is dead: there is no indeterminate state. Again the idea that where there is life there is hope.

Our palliative care team was asked to look after a 36-year-old lady with metastatic sarcoma as it was thought she had only weeks to live. Sandy was married with two teenage daughters. She knew her prognosis. We saw her one Friday afternoon. Her single room was a temple of love. Paintings from the children, flowers, memorabilia. Filled with life. We discussed symptoms and made pharmaceutical adjustments. We spoke about the sadness of saying goodbye to her children. She was dying. When we returned on Monday morning Sandy was calm. The striking thing about her room, though, was that all the color and paintings and artifacts had been removed. It was a sterile lifeless hospital room. She was ready. The days passed and she remained lucid. At the end of the week Sandy asked when it was going to happen, “When am I going to die?” She had banned all friends and family—including parents and children—from visiting. The following week she was a bit weaker but more frustrated—even angry. She found living in limbo, neither dead nor alive, unacceptable. We suggested that the children come back to visit. Sandy refused: Having separated once, it was too difficult to reattach again, too painful. After another week she lapsed into a coma and died.

We may ask, when is living dying? Simplistically, Sandy lost 2 weeks of her life because she had been labeled dying, because the prognosis was imprecise, and because we did not understand how to use the concept of “dying.”

What are the consequences of not having a clear understanding of the word–concept “dying”? Sometimes treatment may continue beyond reasonable benefits. On other occasions treatment may be curtailed too early. Or the designated resuscitation sta-

tus may be inappropriate. Patients and family may be misinformed about death, with disastrous psycho-spiritual sequelae.

Recently an oncology trainee asked with concern: “How do we know when to stop treatment?” This is similar to asking “When is dying?” Who makes the decision to stop? Even today, after many years clinical experience, the decision to stop life-prolonging treatment provokes anxiety. What if I am mistaken? Death is the point of no return.

One must not make assumptions about patients’ understanding of the word “dying.” Too often have I broached the subject—and one must do so in detail—only to discover that the patient assumes he or she is going to die that day, when in fact there may be months to live. In some situations doctors may indeed find that a 6-month guideline (and that is all it is, a guideline) to dying is useful in helping map out treatment options, life choices, and “getting ones affairs in order.” Dying, however, must not preclude living. Oftentimes the word dying is best not mentioned, as it is prone to misinterpretations and may provoke unnecessary demoralization.

Where to from here? In my practice, as a physician in palliative medicine at a comprehensive cancer center, the definition of “dying” that I find clinically useful is: “dying is imminent, physiological and irreversible.” “Imminent” refers to vital organs shutting down, including altered consciousness; “physiological” means it is not depression or demoralization; and “irreversible” indicates no therapy is available to reverse the process. With this definition of dying, death usually occurs within a few days or a week or two at most.

A limited life expectancy (which is all of us) can include plenty of activities with lots of living, until dying (or death) supervenes.

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SIMON WEIN, M.D.  
Co-Editor