Palliative and Supportive Care (2010), **8**, 391–393.

doi:10.1017/S1478951510000246

FROM THE EDITOR

Dignity: A Fight to the End, or an End to the Fight?

> It is unreasonable that he should die after all he had undergone. Fate asked too much of him. And, dying, he declined to die. It was stark madness, perhaps, but in the very grip of Death he defied Death and refused to die.
>
> (London, 1905)

"Dignity" is an attribute commonly ascribed to people who have accepted their imminent death. Kubler-Ross (1981) wrote: "There is something very dignified" about the patient who accepts with "equanimity and peace" their death. However, dignity is equally important for those who want to fight to the very last moment before death. How can dignity be used to describe both scenarios?

Dignity carries with it a sense of self-respect, measured considerations, gravitas, and as its Latin root indicates worthiness. One of the finest examples of dignity from the literature is of course Sydney Carton's self-sacrifice in Dickens' "A Tale of Two Cities." As Carton goes to the guillotine he says: "It is a far, far better thing that I do, than I have ever done; it is a far, far better rest that I go to than I have ever known" (Dickens, 1859).

"To die with dignity" has been used as a *cri de coeur* by interest groups such as the hospice movement, euthanasia campaigners, and anti-medicalization advocates (Clark, 2002; Moynihan & Smith, 2002). They have hijacked the word dignity by linking it irrevocably with the virtue of accepting the end of life and the decision to stop fighting death. Dignity according to this approach may include choosing the time and place of ones death.[1] That is, paradoxically, they re-exert control over their lives by ending life and all the control that is life. Moreover, there is a sense in the hospice-palliative care literature that to fight relentlessly against the inevitable, using maximum medical support is somehow improper. One is being greedy even anti-social to demand to live longer while consuming valuable resources, when failure is likely, even inevitable.

Currently, in our hospital, we are treating, with curative intent (combined chemo-radiotherapy with total parenteral nutrition), two octogenarians with locally advanced esophageal cancer. The hospice-palliative approach would be to encourage the patient to say with dignity (in cricketing parlance): "Listen doc, I've had some great innings, hit a few of sixes, had a couple of near run-outs, but now it's time to turn in my bat." However, some patients desperately want to live. What is undignified about wanting to live and trying ones damndest to do so?

The setting for a difficult discussion ensues when a patient with advanced untreatable cancer says: "I do not want to die. I want to fight. Can't you do something?" People want to live. They do not want to be told about the dignity of passively accepting death. They do not want to be told that "dignity resides in the eyes of the beholder" (Chochinov, 2004). Their dignity is internally generated, based on how they esteem themselves, their life-long values, and not the vanity of how others see them.

When is it time to give up, to stop fighting? A patient with far advanced cancer said, in reaction to such a conversation: "I am not G-d — I do not know when my time is up." Being resigned to ones fate wilts the will to live and shortens life. It encourages "giving up" (as does depression and uncontrolled pain). The "will-to" conversely prolongs life. Why not a few more weeks, even days of the precious stuff?

Clinically, I see two forms of acceptance, which for convenience I have labeled cognitive and philosophical. (1) Cognitive: I know and accept I am going to die but I will fight on as long as I can and live life to the full until I cannot. I will use all that modern medicine and science has to offer. I am unashamedly desperate and I am not overtly "in denial." I am happy to be a guinea pig for any experimental therapy. (2) Philosophical: I have decided to accept my fate and am resigned to my inevitable death. I have no desire or need to fight. I have lived enough, suffered enough,

[1]Dignitas: The name of the organization in Switzerland for assisted suicide. http://www.dignitas.ch/.

and the quality of my life is now more important than the quantity. Fighting is futile and hope is cruel. There are advantages to the philosophical approach: it will avoid low yield, highly toxic therapies; by acknowledging death, fear is often reduced, which encourages communication with family and allows farewells and spiritual wills; it costs less for society (though it is worth noting that if as a species we beat our swords into plowshares there would be plenty for everyone); it encourages an evaluation of life's journey, and enables participation in programs such as a Dignity Therapy (Chochinov, 2004). And somewhere between cognition and philosophy is Randy Pausch in "The Last Lecture" in which he accepted as clearly as possible he was dying and did not try any Phase I trials — yet continued living filled with vigor to provide a last will and testament for his children. Notwithstanding a hard-headed acknowledgment he fought to be creative to the last (Pausch, 2008).

Dylan Thomas also was skeptical about casually accepting death and famously wrote in the name of his father:

> Do not go gentle into that good night,
> Old age should burn and rave at close of day;
> Rage, rage against the dying of the light.
> (Thomas, 1971)

The problem is as follows. Our predictions for the individual are derived from population-based statistics. But we cannot know with certainty which individual will survive or die, and if die, the time of death. Therefore logically speaking the individual can hope to be in the group that "beats the odds" and survives, no matter how miserly the chances. Let us say we had early stage Hodgkin's disease, which is fatal if untreated, but eminently curable (albeit 80%). We like the odds and so fight to live even with the knowledge there is a one in five chance the treatment will not succeed. Similarly, an advanced cancer of the prostate receiving chemotherapy was admitted with septic shock, newly paralyzed from the waist-down. He and his family insist on intubation despite a very small chance of ever getting off the respirator. A chance, not a guarantee; an "odds" just as with Hodgkins. We do not know with absolutely certainty that he will not live another week.

It was obvious he would die, but it always is, in retrospect.

It may be *reasonable* to stop fighting given that the probability of reversibility is small; but the *emotional or moral* desire to fight unto the end even if the chance is of miraculous proportions can be persuasive. Doctors are not infallible. Maybe another doctor will think of something else and save the day. For this person, the dignity of life is the fight. It might be just the way they are, courtesy the genes of Galapagos; it might be they want to communicate by example to their children the importance of valuing every day of life, and they are not concerned at being called greedy or politically incorrect by demanding more resources for themselves, or for scratching and clawing their way in favor of life, against death (London, 1903). Paradoxically if the person successfully struggled to live a few more days because of fear of death or love of life, this may be just the time required to achieve a deeper insight to life and an understanding of death.

A caveat is the obligation of the doctor to direct the patient against dangerous unproven therapies (which may include chemotherapy), which are likely to shorten life. And of course, when a patient with advanced cancer requests that treatment be ceased, then that request should be honored. The line is fine, the art is demanding.

I am concerned that there is a push from the palliative care profession to encourage patients to accept death and give up life, because it is easier — easier for them, easier for us. Moynihan (2002) leans on Ivan Illich (1976) to suggest "...modern medicine has sapped the will of the people to suffer reality, launching instead an inhuman attempt to defeat death, pain and sickness." And Clarke wrote the following caption to a picture of a critically ill person: "Have we come too far in our resistance to death?" (Clark, 2002). It is hard to conceive of more mercenary, negligent, and crass attitudes to life. Are these authors suggesting it is a virtue to embrace suffering and death? A moral position more in keeping with evolution-from-scratch is to keep trying with all our might to overcome disease, suffering — and death. Clarke partly redeems himself when he states that a good death should be "according to personal preference and in a manner that resonates with the person's individuality" (Clark, 2002). A recent article describes a palliative care physician who developed advanced and ultimately fatal breast cancer. Instead of "preaching the gentle gospel of her profession" she refused hospice and mused reflectively about her patients for whom she had been counseling palliative care only: "Am I writing them off too soon?" The palliative physician who cared for her at the end, noted "many people would not have chosen" to keep fighting as she did, with all the pain it incurred (Hartocollis, 2010). She did not die a traditional peaceful palliative death, yet she died as she wanted, struggling with dignity intact.

Thus, with dignity one can accept ones fate and go gently into the night; or with dignity fight tooth and nail until death — and then rest. Dignity applies to both because its source is self-esteem.

https://doi.org/10.1017/S1478951510000246 Published online by Cambridge University Press

REFERENCES

Chochinov, Harvey Max. (2004). Dignity and the Eye of the Beholder. *Journal of Clinical Oncology, 22*, 1336–1340.
Clark, David. (2002). Between hope and acceptance: The medicalization of dying. *British Medical Journal*, *324*, 905–907.
Dickens, Charles. (1859/1997). *A Tale of Two Cities*. London: Signet Classics.
Hartocollis, Anemona. (2010). Months to Live: Helping Patients Face Death, She Fought to Live. *New York Times*, April 4.
Illich Ivan. (1976/2000). *Limits to Medicine*. London: Marion Boyars.
Kubler-Ross, Elisabeth. (1981). *Living with Death & Dying*. New York: Simon & Schuster/Touchstone.
London, Jack. (1905). Love of Life. *McClure's Magazine*, http://london.sonoma.edu/Writings/LoveLife/life.html.
Moynihan, R, Smith, R. (2002). Too much medicine? *BMJ*, *324*, 859–860
Pausch, Randy. (2008). The Last Lecture, Hyperion. http://www.thelastlecture.com/.
Thomas, Dylan. (1971). Collected Poems 1934–1952. New York: New Directions Paperbook.

SIMON WEIN, M.D.
Co-Editor

https://doi.org/10.1017/S1478951510000246 Published online by Cambridge University Press