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 digni-
fied” 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 Car-
ton’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-medicaliza-
tion advocates (Clark, 2002; Moynihan & Smith,
2002). They have hijacked the word dignity by link-
ing 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. More-
over, there is a sense in the hospice-palliative care
literature that to fight relentlessly against the
inevitable, using maximum medical support is some-
how 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 hos-
pice-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 some-
thing?” 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 es-
teeem 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 encoura-
ges “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 philosophi-
cal. (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) Philoso-
phical: I have decided to accept my fate and am re-
signed to my inevitable death. I have no desire or
need to fight. I have lived enough, suffered enough,
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.
REFERENCES


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