THE DEATH OF CRAIG EWERT: REPERCUSSIONS & REFLECTIONS

RIGHT TO DIE OR RIGHT TO LIVE?

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A documentary Right To Die, filming a gentleman who hastened his death by assisted suicide, was televised for the first time in December 2008. This had reignited the endless debate regarding issues of medically assisted death.

Craig Ewert, a 59 year-old American expatriate and retired university professor residing in the UK, was diagnosed with motor neurone disease in April 2006 and was given a life expectancy of two to five years. His disease progressed rapidly and within five months, he was wheelchair-bound and required artificial ventilation and tube-feeding at home. He paid Dignitas, a Swiss right-to-die organization which offers legal assisted suicide.

In September 2006, he flew to the Dignitas Clinic, a residential apartment in Zurich and was assisted to die by drinking a lethal dose of barbiturates. He died 45 minutes later with his wife by his side to say goodbye. He did not want his two children to be present, as he anticipated that it would be more difficult for him to go through with the act.
Excerpts from the documentary and the UK newspapers quoted Ewert’s reasons for wanting assisted suicide:

“I am tired of the disease but I am not tired of living. I still enjoy life enough that I would like to continue but the thing is that I really cannot… If I opt for life then that is choosing to be tortured rather than end this journey and start the next one. I cannot take the risk… Let’s face it, when you’re completely paralysed and cannot talk, how do you let somebody know you are suffering? This could be a complete and utter hell… You can watch only so much of yourself drain away before you look at what is left and say, ‘This is an empty shell’… Once I become completely paralysed, then I am nothing more than a living tomb that takes in nutrients through a tube in the stomach. It’s painful…”

“I am dying. There is no sense in my trying to deny that fact. I truly expect that death is the end, that there is no everlasting soul, no afterlife. This is a journey I must make. At the same time I hope this is not the cause of major distress to my dear, sweet wife who will have the greatest loss as we have been together for 37 years in the greatest intimacy.”

“By this point, I have two choices, either go through with it or say, ‘I am too scared right now and I do not want to do it.’ If I do not go through with it, then my choice is to suffer and to enforce suffering on my family and then die in a way that is considerably more stressful and painful. I have death or I have suffering and death. This way makes a whole lot of sense to me…”

This documentary is powerful in supporting assisted suicide and thought-provoking too. One must not underestimate the power of the media and how the pro-euthanasia lobby is using this film as part of their political campaign. Given such a scenario, what would we choose? Do we really have that choice of deciding the manner and the timing of our own life and death?

In a secular society with a utilitarian and individualistic ethos, there is much emphasis on autonomy, control and self-determination. Ewert’s rationale for wanting assisted suicide seems to make perfect sense. If we could die peacefully with a lethal drink, perhaps we should, but is assisted suicide or euthanasia the only way of ensuring a peaceful death? If we could escape from suffering, perhaps we should, but is suffering always meaningless and should it not be embraced? Life comes with suffering and passion comes with pain, so does it mean that none of us should bother to live or love because we do not want to suffer? Do we only live and love for better but not for worse?
One could go on searching for the right answer. From a legal and medical perspective, however, medically assisted death is not the answer for the following reasons:

1. Patients who have a genuine desire for hastened death represent only a small minority in clinical practice.
2. There is a high prevalence of clinical depression in patients who desire hastened death.
3. The irreversibility of medically assisted death is dangerous as the will to live or die in the terminally ill is known to fluctuate during the course of illness.
4. The terminally ill or elderly are a vulnerable population. They often feel themselves as a burden and they could be compelled to die in order not to burden society. Particularly for the Chinese culture, Confucian philosophy views that a good society takes care of the vulnerable including the sick and that the sick elderly are not allowed to be seen as a burden. Legalizing medically assisted death on the grounds of burden could lead to moral disintegration.
5. The safeguards for protecting the vulnerable against coercion to die, screening for depression and exploring the genuine reasons for desiring death, are not safe or guaranteed.
6. Palliative care is not universally available or accessible for all patients with a progressive life-threatening disease, and even if it is so, its provision tends to focus on the terminal rather than the early phase of the disease journey, which overlooks the fact that patients at the time of diagnosis also have significant psychological distress, fears about their future disease trajectory and death.
7. Medical professionals focus more on the need to respect patient autonomy, assess mental competence for the patients’ requests for death, and determining legal guidelines than listening and understanding the patients’ inner world and genuine needs.
8. Medical students should not be trained to kill but to care when cure is no longer possible.

The real challenge is, as healthcare professionals, how do we respond when we are faced with a patient such as Craig Ewert, who gives an eloquent and seemingly logical reason for his death wish? Do we tell him that it is illegal locally but we would respect his choice of going to Zurich? Should we affirm the Dignitas Founder Ludwig Minelli’s suggestion that we should help to kill those who say they have had enough of an awful life and would like to leave? It is our moral duty to alleviate our patients’ suffering irrespective of the phase of their illness journey. Controlling suffering is a myth; we cannot control but relieve suffering to the best we can; we provide a holding environment to contain their suffering so that it becomes bearable. The holding environment enables the patients to have the opportunity to transcend their suffering into healing and to find meaning and personal growth. Suffering is a complex and multi-dimensional concept, going beyond the physical and functional to psycho-spiritual and existential concerns, understood within the context of the whole person.

Imagine Craig Ewert is your patient... How would you respond? What thoughts are going through your mind? He has only been diagnosed with a life-threatening illness five months ago... Has he been referred to palliative care? Does he accept the diagnosis? Does he have clinical depression? What are his values and personal beliefs? Has he received counseling? Who has been advising him on his options? And who has been supporting him in his decision making? Is he really that terminal that he needs to die now? It is important to listen intuitively and empathetically, trying to read between the lines rather than taking his words at face value. It is necessary to acknowledge the suffering that Craig is going through, spending time to understand his personhood, teasing out the meaning of his every word and exploring in depth his inner world. If we examine Craig’s verbatim carefully according to a framework of (i) the reality, (ii) perception of current suffering for self and significant others, (iii) anticipation of the future, (iv) desires and (v) holding environment and connectedness, it helps to identify his underlying concerns and direct further in-depth exploration:

(i) Craig is aware of the rapid progression of his disease and the inevitability of death.
(ii) Suffering is multi-dimensional: his loss of body image and not just physically but also the loss of sense of existence with a sense of uselessness being totally dependent upon his wife; he sees himself as a burden to his wife; he cannot enjoy life.
Craig has many anticipatory fears: fear of future suffering for self and his wife, anticipating his future as a lifeless body, torture and utter hell. Craig desires relief of suffering for himself and for his wife, not to burden his family and the desire to be understood. His wife provides his holding environment with intimacy but nothing is mentioned about their support network and their children are not present.

From this framework, Craig’s anticipatory fears and support network become apparent areas that warrant deeper exploration, explanation and reassurance. Has he witnessed other patients’ dying trajectory? Has anyone explained that he could come off his ventilator whenever he wanted to and be supported by good palliative care when he was dying so that he would not suffer symptoms such as dyspnoea and choking? Has anyone discussed advanced care planning to ascertain his wishes when he can no longer communicate? What is the support network for him and his family? Apart from his physical and functional concerns, there are many existential aspects that could be addressed to facilitate transcendence of his current suffering.

At a macro level, how should policy makers, medical educators and society respond? Policy makers need to recognize and reinforce palliative care as a standard of good quality care for patients with progressive life-threatening illness, particularly in providing symptom control, psychosocial counseling and existential care. Palliative care can be integrated into non-cancer specialties that deal with life-threatening illnesses at an early phase of the disease journey. Undergraduate medical training could include more emphasis on whole person care and medical humanities to allow better understanding of the patient’s illness experience, thus improving the quality and art of medicine. Public education on life and death would help to promote a positive and healthy attitude to facing crises and caring for the sick. We all have a part to play, as everyone has the right to live, whatever the circumstances.

I end this article with some life-affirming words from Morrie Schwartz, also a retired professor who suffered from amyotrophic lateral sclerosis, but died a natural death at home in the presence of his immediate family:

“Don’t stay pre-occupied with your body or illness. Recognize that your body is not your total self, only part of it.”

“I am an independent person, so my inclination was to fight all of this – being helped from the car, having someone to dress me. I felt a little ashamed, because culture tells us we should be ashamed if we can’t wipe our own behind... ‘Forget what the culture says’... I began to enjoy my dependency... I revel in it... It is like going back to being a child again... We all know how to be a child. It’s inside all of us... It’s just remembering how to enjoy it.”

“Koppel imagined the two men together one day, one unable to speak, the other unable to hear... ‘We will hold hands... And there’ll be a lot of love passing between us... we’ve had thirty-five years of friendship. You don’t need speech or hearing to feel that.’”

References
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