



The Physician and the Dying Patient: A Question of Control?

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"Modern medicine brought the epoch of the natural death to an end"

Ivan Illich [1]

Death is the inevitable end of life, and of the many trials and tribulations that await the young physician completing medical school and embarking on a chosen career, dealing with death and the dying patient may be the most difficult of all. Armed with a rudimentary knowledge of the biology of disease and having acquired the relevant basic skills needed to practise clinical medicine, the preparation for the inevitable confrontation with death has been deficient and inadequate [2]. Indeed, during medical school, the student was most likely exposed to teachers and mentors who emphasised the infallibility of medicine and that since death was final and irreversible it was to be resisted, avoided and postponed at all costs [3]. Terminal illness was regarded as the antithesis of medicine and more emphasis was placed on the maintenance of vital bodily functions rather than the indignity and suffering of the dying patient [4]. Notwithstanding some recent attempts to provide medical students with an early exposure to people who are dying [5], pain control, palliation and hospice care were deemed to be of marginal importance and generally omitted from mainstream clinical teaching [6]. Death, from the perspective of providing unconditional healthcare, was construed as failure and the ultimate surrender.

Modern society places a high premium on youth, health, vigor and achievement, and the training of a young physician focuses on the enthusiasm for life. Many studies have shown that physicians have considerable qualms about dealing with matters of death with both the patient and the family [7]. Redinbaugh et al. [8] reported that the loss of a patient extracts an enormous emotional toll on the treating physician. Nevertheless, physicians work often in the shadow of death oblivious of their own immortality [9]. They distance themselves from death and avoid addressing the subject on various pretexts. Some contend that talking about death when the patient is too ill may remove hope and cause unnecessary alarm or depression, while conversely, discussion with a healthy person is awkward and irrelevant. Furthermore, a general reticence to speak about unpleasant issues, the physician's temerity as well as uncertainty about underlying cultural or religious beliefs, result in a communication gap at a most crucial time in the life of a patient and his or her family [3,10]. Inevitably it is the value system of the

individual physician attenuated by the influences of his/her training, experience and mentors that dictates the relationship between a dying patient and his doctor.

Most individuals are ignorant or oblivious of their options regarding medical care at the end of life [11]. Others live under the illusion that they will have choices in the manner in which their autonomy will be respected when they face impending death [12]. For those who ponder about death, apprehension and fear traverse their minds when they contemplate how they will depart from this world [13]. First, there is the fear that while they are either comatose or heavily sedated and stripped of decision-making capacity, their continuing existence will depend on technology in the form of mechanical ventilation, feeding tubes, dialysis, etc. Second, they dread that their doctors, healthcare providers or family will not respect their explicit advance directives regarding the extent of care they would want if unable to decide for themselves [14]. Third, there exists an underlying fear that their physicians, frustrated with the limitations of modern medicine, will abandon them at the very time when they need pain control, palliation and compassion. Fourth, there is the horrific fear of ending their lives institutionalized in the unfamiliar surroundings of a hospital or nursing home restrained and dehumanized and needing constant assistance in the most personal activities of daily living. Fifth, they are averse to the stress and anguish that will come to family members by their impending demise [15]. Prigerson and colleagues [16] identified caregivers who are at risk for a major depressive disorder or impairment in their quality of life related to the terminal care of their loved ones. Finally, the patients may anguish about the potential financial burdens that they will place on their families should their pension, insurance, etc., not cover medical expenses. Clearly, many factors underscore the concerns patients have of relinquishing control at this most important stage of their lives [17].

Physicians and the medical establishment figure prominently in the distress of individuals facing impending death. For example, although the model for the palliative care of patients with terminal cancer is well developed, Murray and associates [18] reported that patients dying from heart failure have less information and a poorer understanding of their condition and its less predictable outcome than patients with terminal lung cancer. In contrast to this latter group, cardiac patients received less health, social and palliative services. Consequently, frustration, loss of social interactions,

abandonment and isolation express the loss of control in this group of individuals [19]. Indeed, Jennings et al. [20] advocated expanding the boundaries of hospice care and extending palliation to all individuals with inevitable impending death, regardless of cause.

In Oregon, the Death with Dignity Act went into effect in October 1997. This law allows for a terminally ill person to request a lethal prescription of medications for the purpose of self-administration at a time of his/her choice [21]. Enactment of the law has served to fortify the positions of the participants in the debate. The protagonists for the sanctity of life renounced the statute, foreseeing a "slippery slope" where doctors would not only condone active participation in helping someone die but take a life on request. The hospice movement in their plea for a compassionate, pain- and symptom-free death argued that assisting patients to die was beyond the boundaries of the medical profession. For members of the Hemlock Society, the Oregon law, providing only oral medications and not lethal injections, fell far short of providing a pain-free non-suffering death where the individual would be in control all the time. By the end of 2003, five years after passage of the law, 129 persons or 65% of those requesting lethal prescriptions had used them to end their lives. The estimated rate of physician-assisted suicide was less than 1 per 1,000 deaths in the state. Studies from Oregon indicate that despite the availability of physician-provided medications with which to end their lives, the overwhelming majority does not request them and many individuals who do never intend to use them [22]. The originally intended "dire circumstances" or the "last resort" after all attempts at pain control had failed was not what motivates them to request lethal medications but rather a desire to control the quality of their last days. Despite the accessibility of hospice care to all citizens of Oregon, persons on death's doorstep fear losing control and independence at this most crucial time of their lives [23].

What motivates someone to end his life rather than be a burden on someone else? What is it that makes modern society so afraid of suffering that suicide becomes the only option? Affluence and the conveniences of modern living have granted us zero tolerance for suffering. Technological advances in communication via the televised and written media have exposed nearly all of us to vivid images of cruel and awesome ways of dying. Abhorred by these scenes, society is demanding that persons maintain control throughout the duration of their lives and not only while young and productive. Individuals insist on society allowing them to assert their autonomy and personal liberty in how they die in the same manner that it encourages assertiveness and independence during life. The message of the Oregon experience is clear. For individuals near death, assisted suicide, even where it is legally available, is the choice of the overwhelming minority. What people want is a good death [24] – a death that is free of stress and suffering for them, their families and caregivers [25]; a death of awareness and dignity, a death in general accord with their wishes and directives, a death consistent with their cultural, religious and ethical standards [26]. They want compassion and understanding [27]. It is incumbent on us all to advance the pursuit of these noble goals. The time has come to give high priority to the education of medical students, physicians, healthcare providers and, indeed, the public at large in

matters of death [28]. It is our responsibility. Our children and grandchildren will be our benefactors.

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