
ESSAY/PERSONAL REFLECTIONS

The dying patient: The right to know versus the duty to be aware

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Neither the sun nor death can be looked at with a steady eye.

Francois de la Rochefoucauld

INTRODUCTION

Should terminal patients know about their impending deaths? How much should they know? How do we determine “should”?

In Western society the right to know is a moral value, and knowledge about an impending death has practical advantages for the patient, his family, society, and the medical system. Israel’s Patient’s Rights Act (1996) established the rights of patients to be informed of diagnosis, prognosis, and treatments related to their medical conditions. This in turn obligates the patient’s physician to provide the information. The law also provides physicians with the option to convene an ethics committee to sanction withholding information when it is likely that the information may worsen the patient’s condition (Patient’s Rights Act, 1996; Wenger et al., 2002). The Dying Patient Act of 2005 further established the physician’s duty to inform dying patients of their condition, and added the option to prepare an advance directive or appoint a proxy to handle cases where the patient’s ability to decide is impaired (Steinberg & Sprung, 2006).

Some societies have established rights, ethical and moral, in order to preserve equality. According to the traditional view, rights and duties are inextricably bound one to the other. When human needs are not met, rights are created and may be recognized socially and legally. Fulfillment of needs may be

requested, whereas rights are demanded. Society today puts great weight on the individual’s right to know. A law is passed supporting this, which then obligates the doctor to tell the patient the truth.

When we reflect on the law pertaining to the dying patient’s “right to know” several questions arise. What happens to the individual who does not want to know? Or the individual who only want to know a part of the truth? How do we balance the duty to tell terminally ill patients about their prognosis, with the countervailing right not to be told? Can a patient autonomously forgo their autonomy? Is the obligation to tell all that there is to know? Can the societal law in this sense entrap the individual? When did the subject of awareness of one’s impending death move from the private realm to the public arena?

THE MEANING OF DEATH IN MODERN SOCIETY: A SOCIOLOGICAL ASPECT

Society has always viewed death as a significant event. Today, increased longevity, an aging population, and the creation of chronic ailments create new scenarios in dealing with death. John and Riley (1983) studied the subject of death in modern society and cite three major areas of interest. First is the individual’s view of his own death. Second is dealing with the death of another, as in mourning and bereavement. Third is development of social structures that relate to death and dying.

John and Riley (1983) note that medical advances have increased the ability to predict and control the time of death, especially of chronically ill patients. Hence patients may participate in deciding how to manage their terminal illness. Death in slow motion has challenged the traditional dichotomy between living and dying. Prolonging and postponing the

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dying process have demanded new approaches in the search for meaning in aging and dying. The traditional role and duty of physicians is similarly challenged.

Emanuel et al. (2007), using “role theory” and Parson’s Model (Parsons & Renee, 1952) state that significant differences have emerged in modern society between the “patient’s role” and the “dying role,” and confusion between the two terms may harm patients in their last days. Does the patient’s role include a commitment to actively participate in one’s own death? How much should the dying person be aware of his impending death? What is a good death, and who defines it as such?

THE ETHICAL-MORAL PERSPECTIVE

The moral argument is based on the importance that theories of liberal morality and bioethics assign to autonomy and therefore one’s right to control and manage one’s life. Therefore patients have the right to be told “the whole truth and nothing but the truth,” especially in informed consent. Adherents of autonomy are concerned about and emphasize the vulnerability and dependence in asymmetrical relationships. The centrality of autonomy, however, is not without its critics.

According to care ethics, for example, caring for another, especially the needy and the vulnerable, is the foremost universal moral principle (Tong, 1998).

Brody (1988) focuses on treatment at the end of life and opposes the approach of absolute autonomy. He argues that moral decisions are not based on one moral truth, but combine contradictory truths that create conflicting situations. There are situations in which one’s autonomy should be emphasized—entering a clinical trial or risk–benefit analyses regarding chemotherapy. But there are conditions—terminal illness, cognitive trauma, and delirium—when emphasis should be on moral conduct (compassion, courage, honesty). Brody (1988) suggests addressing terminal illness as a condition in which the preservation of hope can take precedence over the duty to provide information. For some families, pretending that death is not imminent preserves their dignity, which is more important for them than the principle of autonomy.

ON DEATH AND THE INDIVIDUAL’S AWARENESS OF DEATH

Philosophers, more than other professionals, discuss how individuals cope with their own deaths and to a lesser degree how they deal with the death of others. The philosophical study of death is as old as science itself.

Epicurus (2007), who lived in Greece in the second century BCE, wrote in a letter to Menoeceus: “Death, therefore, the most awful of evils, is nothing to us, seeing that, when we are, death is not come, and, when death is come, we are not. It is nothing, then, either to the living or to the dead, for with the living it is not and the dead exist no longer.” Epicurus’ words raise the question, “Does man have the cognitive ability to truly comprehend and imagine his own death?”

Plato, on the other hand, presented an idealised view that we could understand death. In his view, the science of philosophy is like training for one’s death. Death is the separation of the spirit from the body. Knowing the pure eternal truth is possible only by the spirit, and only after it has separated from the body. In his view, only the philosopher truly knows the science of death, either literally as in dying or theoretically as in contemplation. The encounter with death enables him to know the pure truth.

Spinoza (2003), in his book *Ethics*, argues that “Nothing is less thought of by a free man than death, as his wisdom does not observe death but life.” It does not mean that the free man suppresses the fact of mortality, as the understanding of self is the basis of freedom. Spinoza means that he evades death anxiety by not thinking about death lest it overshadow life.

Camus (1978), of the existential school, maintained that the only serious philosophical problem is suicide. The fact that man clings to life despite his awareness of death proves that there is something stronger than all worldly problems. In the “Myth of Sisyphus,” according to Camus (1978), evading death is the hope. Therefore, it follows that hope may be strengthened even at the expense of full awareness of death.

The sociologists Glaser and Strauss (1965), who base their investigation on grounded theory, discuss the question of whether people can die socially before they die biologically. According to them, the major difference between social death and biological death is in the individuals’ consciousness of the final and imminent departure from those around them. The level of consciousness and the cognitive processing of information affect the emotional content of the death process.

Kubler-Ross (1969), a psychiatrist, noted that in hospitals, death had become technological, cold, and alienated, and that it took place within a death-denying society and medical system. Kubler-Ross developed the five-stage model, comprised of denial, anger, discussion, depression, and acceptance. According to the model, the denial of death was considered an obstacle to acceptance. Kubler-Ross’s model does not distinguish between the

individuals' coping with their own deaths and coping with the death of another.

Weisman (1972, 1989) criticized the Kubler-Ross five-stage model. In his opinion, the purpose of psychotherapy in cancer is not acceptance of death but rather living fully the time that is yet to be lived. In his view, denial in its various levels is a dynamic, differential coping mechanism that does not take place in a vacuum. Denial is not a psychological state of the individual only, for it requires two persons: the one who denies and another person who holds the information and makes the judgment as to whether the denial is healthy or harmful. Weisman argues that in treating dying patients, denial should be respected but not become something to hide behind. Breaking denial would be inappropriate, unless denial contributes to increased suffering.

HOW AWARE ARE PATIENTS OF THEIR IMPENDING DEATHS AND HOW DOES THIS AWARENESS AFFECT THEM?

There are many disagreements and opinions about what dying patients should know. The literature points in two different directions: characteristics of the patient and his family members (information receivers) and characteristics of the medical system (information providers). Studies discussing awareness of prognosis and impending death and whether denial exists, therefore, deal in what physicians say and what patients understand. Several studies have shown that doctors consciously tend to provide optimistic and inexact information on life expectancy in order to preserve hope (Christakis & Lemont, 2000; Lamont & Christakis, 2001). It was also found that truthful information on life expectancy may lead to more informed end-of-life decisions and avoid false hopes or "hope traps," which in turn may increase suffering (Weeks et al., 1998).

Chochinov et al. (2000) have found in a study of dying patients that most (73%) of the patients were fully aware of their prognosis and the short life remaining to them, 17% had partial awareness, and only 9.5% experienced full denial. Depression rates among patients who were unaware or partially aware were three times more frequent than fully aware patients. The researchers raise the possibility that psychological difficulties may hinder awareness of illness severity whereas awareness of impending death creates openness, sincerity, and reduces depression.

Burns et al. (2007) investigated awareness and comprehension of treatment goals among cancer patients with expected life expectancies of half a year. Only in a third of the cases were both patients and family members aware that the treatment was not intended to cure.

Ray et al. (2006) conducted a longitudinal study among 280 dying people. The researchers investigated the patients' awareness of their conditions in two areas: Do they perceive themselves as dying? Are they at peace with their condition? Six months after death, the researchers interviewed a primary member of each family on his or her perception of the death of the loved ones. Overall, 17.5% of patients were reported as being both peaceful and aware. Peacefully aware patients had lower rates of psychological distress and higher rates of advance care planning (e.g., completing do-not-resuscitate orders, advance care planning discussions with physicians) than those who were not peacefully aware. Additionally, peacefully aware patients had the highest overall quality of death as reported by their caretakers in a postmortem evaluation.

Fried et al. (2006) investigated whether patients become more aware of their impending deaths as their diseases progress. The researchers found that most deceased patients were not aware, or were partially aware, of their impending deaths. Most of them were too optimistic about their prognosis just 1 month before their deaths, and they demonstrated no change of awareness as the disease progressed. A small minority of them were aware of the approaching end. Among family members, awareness of impending death was higher. However, just one half of the family members who had lost their relatives during the month before the interview could state that the expected time remaining was less than a year.

In a meta-analysis on studies about caregivers "preparedness" for the death of dear one, Hebert et al. (2006a) concluded that families who were better prepared had an easier mourning process. Furthermore, death at hospice reduces morbidity among family members (Christakis & Iwashyna, 2003). However, as Hebert et al. (2006b) note, most studies that investigate the relationship between preparedness for death and morbidity are based on retrospective studies of family members who are "getting on with their lives."

BETWEEN THE PRIVATE AND THE PUBLIC: A CRITICAL APPROACH TO ACHIEVING AWARENESS OF DEATH

Zimmerman (2004, 2007) challenges the philosophy of palliative care that promotes awareness of impending death. She bases her arguments on texts from the palliative literature, dealing with denial, palliative treatment and hospice. She looks for hidden values that preserve the "narrative and practice" of palliative treatment and especially the use of the term "death denier." Two different pictures are presented: denial as a coping mechanism and denial as an obstacle to palliative treatment. She stresses that the denial concept evolved in psychoanalysis, where it

is defined as an unconscious defense mechanism that protects the individual from painful information. The psychoanalytical treatment aims to flood and bring to the surface unconscious content in order to resolve it, so as to prevent damage to the physical, mental, and social health.

Zimmerman (2004, 2007) claims that in modern society—supported by the palliative approach—denial of death is considered an undesirable problem in the private and social realms. The process, she explains, began in the 1960s, when Kubler-Ross published her works and the hospice and palliative movements were initially developed. The medical system was blamed for its role as a “death denier,” because death represented a technological failure. Instead of the alienating technology-laden death away from home, the hospice movement and later palliative medicine offered a new way. They provided attitudes and treatments that were directed at acceptance of death, achieving a “good death” and “death with dignity.” These were made possible by encouraging autonomy and acknowledging death during treatment. This led to an approach that valued quality of life over longevity. The hospice and palliative philosophy held the medical staff responsible to do all it could to help the patient accept death, relinquish life, and part proactively from people close to them. It is preferable that the patients face death with courage and restraint. They saw the conspiracy of silence around the dying as a conspiracy of the living against the dying that may cause loneliness and alienation, a thing to be avoided.

Zimmerman (2007) claims that in the palliative-hospice literature, denial is usually cited as an obstacle in the path of good palliative treatment. Denial is damaging to an open discussion on death, to dying at home, to preparing predeath instructions, to achieving closure, and to treating symptoms and discontinuing ineffectual treatment. According to the hospice approach, awareness of impending death may prevent unnecessary medical interventions and save precious resources for society. The palliative approach strives for awareness and expects the patient to be actively involved in the death process. Zimmerman argues, however, that by denying denial, that is, disallowing a patient the choice of denial, patient privacy is compromised and judgmental attitudes are encouraged. Thus, paradoxically, by enforcing autonomy and ignoring human differences, we may end up labeling those who are uncooperative, as “deniers.”

CONCLUSION

Knowledge and research of preparedness for death is still in its early stages. We do not have enough infor-

mation regarding preparation for death—what is helpful and what is harmful, both for the individual and the family. Preparing for death involves personnel from a range of disciplines, and it is imperative to investigate the role and contribution of each one of these professionals in the process. We believe that when discussing awareness and denial of death, it is important that family members and patients share the experience, as it is a sensitive and complex process. In this process, vulnerability and uncertainty play their parts, each with advantages and disadvantages. And hope, like information, may have a price.

The discourse on death denial has evolved from a legitimate private matter to a “problem” of public interest (Stone, 1989). As the discourse moves from the private realm to the public, it impacts legislation, which in turn shapes the way we will die. It leads to greater openness about impending death and involvement in the death process, despite fears and the tendency to deny death. The medical system, as part of modern society, has a vested interest in people being aware of their impending deaths. Yet it is not sufficiently clear to us what is best for the dying patient. Oftentimes denial of imminent death is seen as healthy.

Because denial is complex and a multilevel concept and because physicians are required by law to provide information on diagnosis and prognosis, a situation is created where patients may be denied their right to be unaware. Hence, it is possible to imagine a situation where medical personnel who act in accord with their professional ethic may coerce a patient to hear the truth, against his or her wishes.

A “good death” is when the subjective (patient) and the objective (society, family) appear to blend seamlessly—before, during, and afterward. Hope and truth, similarly, are not mutually exclusive concepts; rather they are struts supporting a good death.

REFERENCES

- Brody, B. (1988). *Life and Death Decision-Making*. New York: Oxford University Press.
- Burns, C., Broom, D.H., Smith, W., et al. (2007). Fluctuating awareness of treatment goals among patients and their caregivers: A longitudinal study of a dynamic process. *Supportive Care in Cancer, 15*, 187–196.
- Camus, A. (1978). *The Myth of Sisyphus*, Afikim Book. Tel Aviv: Am Oved.
- Chochinov, H.M., Tataryn, D.J., Wilson, K.G., et al. (2000). Prognostic awareness and the terminally ill. *Psychosomatics, 41*, 500–504.
- Christakis, N.A. & Iwashyna, T.J. (2003). The health impact of health care on families: A matched control cohort study of hospice use by decedents and mortality outcomes in surviving widowed spouses. *Social Science in Medicine, 57*, 465–475.

- Christakis, A.N. & Lemont, E.B. (2000). Extent and determinant of error in doctors' prognosis in terminally-ill patients: Prospective cohort study. *British Medical Journal*, 320, 469–473.
- Emanuel, L., Bennett, K. & Richardson, V.E. (2007). The dying role. *Journal of Palliative Medicine*, 10, 159–168.
- Epicurus. (2007). *Letter to Menoeceus*, translated by Robert Drew Hicks. Retrieved from ebooks.adelaide.edu.au/e/epicurus/menoceus.
- Fried, T.R., Bradley, E.H. & O'Leary, J. (2006). Changes in prognostic awareness among seriously ill older persons and their caregivers. *Journal of Palliative Medicine*, 9, 61–69.
- Glaser, B.G. & Strauss, A.L. (1965). *Awareness of Dying*. Chicago: Aldine.
- Hebert, R.S., Dang, Q. & Schulz, R. (2006a). Preparedness for death of loved one and mental health in bereaved caregivers of dementia patients: Findings from the REACH study. *Journal of Palliative Medicine*, 9, 683–693.
- Hebert, R.S., Prigerson, H.G. & Schulz, R. (2006b). Preparing caregivers for death of a loved one: A theoretical framework and suggestions for future research. *Journal of Palliative Medicine*, 9, 1164–1171.
- John, W. & Riley, J.R. (1983). Dying and the meaning of death: Sociological inquiries. *Annual Review of Sociology*, 9, 191–216.
- Kubler-Ross, E. (1969). *On Death and Dying*. London: Collier-Macmillan Ltd.
- Lamont, E.B. & Christakis, N.A. (2001). Prognostic disclosure to patients with cancer near the end of life. *Annals of Internal Medicine*, 134, 1096–1105.
- Parsons, T. & Renee, C.F. (1952). Illness, therapy and the modern urban American family. *Journal of Social Issues*, 14, 31–44.
- Patient Rights Act. 5756 Sefer HaChukkim: 327, 1996.
- Ray, A., Block, S.D. & Friedlander, R.J. (2006). Peaceful awareness in patients with advanced cancer. *Journal of Palliative Medicine*, 9, 1359–1368.
- Spinoza, B. (2003). *Ethics*. Tel Aviv: Hakibbutz Hameuchad.
- Steinberg, A. & Sprung, C.L. (2006). The dying patient: New Israeli legislation. *Intensive Care Medicine*, 32, 1234–1237.
- Tong, R. (1998). The ethics of care: A feminist virtue of care for healthcare practitioners. *Journal of Medicine and Philosophy*, 23, 131–152.
- Weeks, J.C., Cook, E.F., O'Day, S.J., et al. (1998). Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA*, 279, 1709–1714.
- Weisman, A. (1972). *On Dying and Denying*. New York: Behavioral Publications.
- Weisman, A. (1989). Denial, coping and cancer. In *Denial: A Clarification of Concepts and Research*, Edelstein, E.L., Nathanson, D.L. & Stone, A.M. (eds.). New York: Plenum Press.
- Wenger, N.S., Golan, O., Shalev, C., et al. (2002). Hospital ethics committees in Israel: Structure, function and heterogeneity in the setting of statutory ethics committees. *Journal of Medical Ethics*, 28, 177–182.
- Zimmermann, C. (2004). Denial of impending death: A discourse analysis of the palliative care literature. *Social Science & Medicine*, 59, 1769–1780.
- Zimmermann, C. (2007). Death denial: Obstacle or instrument for palliative care? An analysis of clinical literature. *Sociology of Health & Illness*, 29, 297–314.