Death and Dying — Stages of Dying, Palliative Care and More

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Due to medical advances over the last half century, people expect to be cured of all their illnesses and live forever. However, death and dying are inevitable. For people facing death as well as for those around them, the process of dying can be stressful. We as physicians can ease the process for our patients, caregivers and ourselves. To be able to do this, we have to understand what dying entails, and then prepare for the event.

Stages of Dying

Dr. Elisabeth Kübler-Ross described the following stages of grief related to dying: **shock, denial, anger, bargaining, depression, acceptance, and decathexis**.

When individuals and their relatives first receive the news of a fatal disease, they are shocked. Next, they cannot accept the fact that the illness could affect them (denial). They then become angry with the universe, environment, and/or physicians. In the next stage, they "bargain" with the universe or with God for a cure and prolonged life. As the disease progresses, they become depressed; eventually, they accept their fate. In the final stage, they emotionally withdraw (decathexis) and blank out all thoughts of death.

A person going through all of these stages is able to set his/her affairs in order; make peace with friends, relatives, and enemies; and say goodbye. Unfortunately, not everyone is able to go through all of these stages. When deaths occur suddenly (e.g., in a traffic accident), there is no time for the individual to say goodbye, and there is no closure for his/her loved ones.

Process of Dying

A majority of patients will follow one of the following paths:

- Progressive steady functional decline over a limited time period (e.g., in malignancies)
- Indefinite prolonged and severe functional decline (e.g., Alzheimer's disease, disabling stroke, musculoskeletal/neurologic diseases)
- Irregular, unpredictable, sudden exacerbations that decrease functional abilities (e.g., cardiac failure, chronic obstructive pulmonary disease [COPD]).
- Sudden death in otherwise healthy individuals (e.g., after myocardial infarction or cardiac arrest, traumatic/accidental deaths)

It is difficult for physicians to predict the timing of death. However, if a patient has a fatal illness that is likely to worsen such that death could be imminent within the next 12 months, the physician could provide an estimated time period. In addition, the physician should do the following:

- **Inform the patient** (and his/her family, with the patient's consent) about the course of the illness and the probable survival period
- **Discuss end-of-life care (palliative/hospice/resuscitation)** with the patient and his/her caregivers. The patient should have the opportunity to participate and choose his/her preferences.
- **Arrange for care**
- **Provide medications to manage symptoms.** Opioids are the mainstay for pain management, but they are associated with adverse effects, such as constipation, which will also require medication.
- **Address the patient's ethical, financial, and legal concerns**
- **Manage the patient's and caregivers' stress** by arranging religious support and/or prescribing anxiolytics

Fears/ Goals at the End of Life

Different people have different goals:

- Some people want to be independent as long as possible.
- Some want spiritual solace and reconciliation or want to ensure that their loved ones are provided for.
- A few want to prolong life irrespective of the cost and stress caused to their families.

However, almost all people are **afraid of dying alone and being in pain**. Most patients want to discuss end-of-life care when they are mentally and physically healthy, and they often prefer to involve their family members. It is important for physicians to understand this and involve the patients and their families in this process.

Financial Concerns

Health care costs have been steadily increasing, and families can spend all their savings to prolong the life of a loved one. Families should be advised to **investigate the costs of medical care and the insurance coverage available to care for a dying family member** and determine what options are affordable.

Fatal illnesses are associated with progressive functional disability, and patients may not be able to care for themselves. Services such as occupational therapy, physical therapy, and home care add to the cost. The health care team should address these issues when discussing options and choices for patients.

Legal and Ethical Issues

It is important for physicians and health care teams to **be aware of laws concerning physician-assisted suicide, euthanasia, power of attorney, living will, and advance directives** because they can vary geographically. Only a few U.S. states have laws allowing physician-assisted suicide. Other states require that opioids must be titrated to provide pain relief and avoid respiratory depression.

Palliative Care and Hospice

Palliative care encompasses measures to relieve physical, emotional, and spiritual issues. It can be—and ideally should be—provided concomitantly with curative treatments. **Palliative care teams are interdisciplinary and consist of physicians, nurses, social workers, chaplains, etc.** who together help relieve the patient's stress.

On the other hand, **hospice care is restricted to those who have 6 months or less to live and aims to provide relief but not cure**. Hospice care includes services such as nursing, physical care, medications, spiritual counseling, and providing medical equipment (e.g., oxygen cylinders, masks, etc.). Hospice care can be either hospital or home-based. Patients receiving hospice care have the option of leaving it and re-enrolling later.

Planning for Death

Symptom relief is the most important aspect of death planning. A comfort kit consisting of opioids and oxygen is provided by the hospice team for home-based care, along with instructions for using it.

Family members and caregivers should receive **information about delirium, confusion, dyspnea, bluish discoloration of the skin, death rattle,** etc.

If possible, organ donation, autopsy, and funeral arrangements should also be discussed before death to diminish stress.

Supporting Caregivers

The death of a loved one can be very difficult for families and caregivers. Once a physician has confirmed the death, a **death certificate is provided to enable the funeral director to prepare the body and carry out the funeral arrangements**.

Family members should be informed of the death with **respect, composure, and sensitivity**. Families and caregivers may need psychological support and anxiolytics as they grieve and come to terms with the fact that a loved one has died. This is especially important in sudden deaths.

Successful Dying

The concept of a ‘good death’ is not new and has been addressed in the arts, social sciences, and health sciences. An accurate definition of ‘successful dying’ is difficult to find; however, there are clear themes in how patients and caregivers think about successful dying.

Some might ask whether successful dying is the consequence of successful aging. Others might associate successful dying with the preservation of dignity. Still, others might consider a good death to be death that comes after the completion of life goals and the exhaustion of treatment preferences. Accordingly, we will discuss the core themes of successful dying based on the most recent published scientific literature.

Successful Dying and the Dying Process

Some might believe that a successful death is determined by the dying process itself. For instance, the scene (how, who, where, and when) of death is known to play an important role in the definition of successful dying. Many people consider dying during sleep to be a good death. Some patients also include preparation for death through funeral arrangements in the definition of a good death.

Pain and Successful Dying

Many patients, especially those with chronic or malignant disease, hope to die without suffering and pain. To them, therefore, successful dying means managing symptoms and being free from pain.

Emotional Support and Successful Dying

The provision of emotional and psychological support to the patient is very important. Therefore, a common theme of successful dying is emotional well-being. Family support, the acceptance of the idea of death by family members, and the preparation of the family for death are also associated with successful dying.

Dignity and Successful Dying

For some patients, it is important to be respected as an individual and lead a life of independence. Such patients, for example, might prefer not to receive cardiorespiratory resuscitation if they experience cardiac arrest. For these patients, dying while still independent of others is an important part of a good death.

The Concept of Life Completion

For many patients, successful dying includes living a good life, saying their goodbyes, and accepting death.

Treatment Preferences

Some patients do not want to prolong life at the expense of their dignity, so for them, a good death is not associated with taking extraordinary measures to prolong life. Moreover, a patient who truly believes that he or she has tried all available treatments and that death is inevitable can accept death and die successfully.

Religion and Successful Dying

Patients might take comfort in religious or spiritual beliefs that help them accept the concept of dying. For instance, those who believe in an afterlife might find it easier to

accept death and die successfully. However, this can be a double-edged sword. Patients might consider faith to be an important factor that determines a successful death.

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