

BIOÉTHIQUE MEDICAL ETHICS BIOÉTHIQUE MEDICAL ETHICS BIOÉTHIQUE GAPS IN END-OF-LIFE CARE

<http://www.lebanesemedicaljournal.org/articles/59-1/doc9.pdf>

Michel DAHER*

Daher M. Gaps in end-of-life care. J Med Liban 2011 ; 59 (1) :

...-...

ABSTRACT: End-of-life care is an important aspect of medical practice. Individual physicians and the medical community must be committed to the compassionate and competent provision of care to dying patients and their families. Patients rightfully expect their physicians to care for them and **provide them medical** assistance as they are dying.

To care properly for patients near the end of life, the physician must understand that palliative care entails addressing physical, psychosocial, and spiritual needs and that patients may at times require palliative treatment in an acute care context. To provide palliative care, the physician must be up to date on the proper use of opioids and the legality and propriety of using high doses of opioids as necessary to relieve suffering. Good symptom control; ongoing involvement with the patient; and physical, psychological, and spiritual support are the hallmarks of quality end-of-life care.

Care of patients near the end of life, however, has a moral, psychological, and interpersonal intensity that distinguishes it from most other clinical encounters.

With appropriate education, physicians can play a key role to improve care for patients and families who are living with advanced life-threatening illness. Although some issues (e.g., the role of physician-assisted death in addressing suffering) remain very controversial, there is much common ground based on the application of the four major principles of medical ethics, nonmaleficence, beneficence, autonomy, and justice.

There is a **disparity** between the ways in which people die, and the ways in which they **want to die**. With appropriate education, physicians can play a key role to improve care for patients and families who are living with advanced life-threatening illness.

Every day hundreds of thousands of people die of a variety of causes. Some die easily and comfortably; others die with a great deal of **suffering and distress**.

*Faculty of Clinical Surgery and Director, Medical Ethics & Bioethics Teaching Program, University of Balamand Saint George Hospital, Beirut, Lebanon.

Correspondence: *Michel Daher, MD. University of Balamand Saint George Hospital, UMC. P.O. Box 16 6378 - Beirut, Lebanon.*

e-mail : mndaher@inco.com.lb

In the early 1900's, average **life expectancy** was 50 years. Childhood mortality was high. Only **a few** people lived to the ages that we regard as normal today. Historically, up until the development of antibiotics in the mid-20th century, people typically died quickly, often of infectious diseases or accidents. As only a few remedies were available to extend life, medicine focused on caring and comfort. While customs and traditions varied across cultures, most cared for their sick at home with support from their physician, if one was available.

During the second half of the 20th century, the age of science, technology and communication, new science and technology have offered the potential of medical therapies previously unknown. Where once physicians could only provide comfort in the face of serious illness, the modern healthcare system can now "**fight aggressively**" against illness and death.

We frequently attempt to prolong life at all cost. We often succeed. Already the effect has been significant. Improved sanitation, and the development of a wide range of antibiotics and other medical interventions, **have** increased life expectancy in Lebanon to an average of 72 years by 2008 (73 years for women compared with 71 years for men); life expectancy in some European countries, Canada and others increased to more than 80 years, and every year the statistics continue to improve.

A plethora of new medications and therapies have changed the way we experience illness. The shift in focus has been so complete that death has become the enemy to be beaten at all costs. Many organizations have held out promises that illness can be beaten. Many physicians and healthcare workers have come to believe that they have failed if they do not save their patients from death.

Death has not been conquered, **all of us will die**. While our health care system and biomedical science enterprise **has learned** to cure a few illnesses, **it has** primarily learned to prolong the experience of living with chronic illness, and the **process of dying**.

A few of us (< 10%) will die suddenly of a myocardial infarction, an accident, or another unexpected event. Most of us (> 90%) will experience a protracted life-threatening illness with either a relatively predictable steady course and a relatively short "terminal" phase (cancer), or a slow decline punctuated by periodic crises (congestive heart failure, emphysema, Alzheimer-type dementia, etc.)

As we imagine our own future and death, or the death of one of our children, fears and fantasies driven by past experiences and media dramatization frequently heighten anxiety about the events that may occur.

In all studies of symptom prevalence, pain, nausea/

vomiting, constipation, and breathlessness are very significant. As patients lose weight and become weak/fatigued, loss of function becomes increasingly present. For many people, the **loss of their independence** is devastating and a source of considerable suffering.

| BALANCING BENEFIT AND BURDEN | |
|------------------------------|-----------------------|
| Benefit | Burden |
| Longer life | Pain |
| Comfort | Suffering |
| Relationships | Technology dependency |
| Community | Isolation |
| Communication | Immobility |
| etc. | etc. |

In addition to **physical symptoms**, many patients and families also experience considerable **psychological distress**, including anxiety, depression, worry, fear, sadness, hopelessness, etc. In one study, 40% of patients with advanced illness (where death was expected) were afraid of being a burden to their family and friends.

While most of us believe it is a family's responsibility to provide care for someone who is dying, this social event creates a very different situation from the one that existed in the past. Today, when a patient needs assistance, **the burden of care giving** frequently falls to a very small number of people, often women, who may be unskilled and without the resources they need to provide that care.

In addition to the issue of who will provide care, **financial issues** associated with care giving have a significant impact on the family. Some family members had to **quit work** or make another major life change in order to provide care for a loved one.

In contrast to the **desire to die at home**, (expressed by 90% of the respondents to a Gallup survey commissioned by the National Hospice Organization [NHO] in 1996), death moved out of the home and into institutions. Although there is some regional variation, the majority of patients dying in hospitals are dying with illnesses where the expected outcome is death. They could be "**managed at home**".

| LARGE GAP BETWEEN REALITY, DESIRE | |
|-----------------------------------|-------------------------|
| Fears | Desires |
| Die not on a ventilator | Die on a machine |
| Die in discomfort | Die in comfort |
| Be a burden | Die with family/friends |
| Die in institution | Die at home |

When the current status of care for the dying is summarized, the large gap between the way people currently live with life-threatening illness and die, and the way they would like to experience the end of their lives at home becomes apparent.

With the shift to fight death "the enemy" at all cost, treatments have frequently become excessively aggressive, symptoms have not been controlled, and patients have lost their independence.

There are many other reasons why end-of-life care is not what it could or should be. To name but a few:

- Frequently, neither the public, nor health care providers acknowledge that end-of-life care is important. It is often introduced too late to be effective, and funding is frequently inadequate to deliver quality palliative care.

| BARRIERS TO PAIN RELIEF- SPECIFIC BARRIERS |
|---|
| <p>Professionals</p> <ul style="list-style-type: none"> • Poor assessment • Lack of knowledge <p>Health Care Systems</p> <ul style="list-style-type: none"> Regulatory oversight <p>Patients</p> <ul style="list-style-type: none"> • Fear of addiction • Tolerance • Adverse effects |

- **Fears of addiction**, exaggerated risks of adverse effects, and restrictive legislation have resulted in inadequate control of symptoms (mainly pain management).
- **Discomfort communicating** bad news and prognosis, lack of skill to assist patients and families to negotiate clear goals of care and treatment priorities, and lack of understanding of patients' rights **if the patient is a child**) to decline or withdraw treatment have led to frequent misunderstanding and excessive futile intervention.
- Personal fears, fantasies, worries, and lack of confidence have prompted many physicians to avoid dealing with patients who are dying.

As one contribution to help bridge the gap between patient and family expectations and the current state of end-of-life care several educational symposia and workshops were organized in Lebanon in the past decade and were intended to help physicians and other health professionals to take care of their portion of the responsibility to develop good end-of-life care. This will equip them with a core base of knowledge that, in its application, will help physicians to improve their competence and confidence, strengthen physician-patient relationships, and enhance personal satisfaction with end-of-life care.

*"Physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care. This include providing effective palliative treatment even **thought** it may foreseeably hasten death"*
Code of Medical Ethics 1994

To move beyond the confusion, the concept of **palliative care** has started to evolve as a response to the continued deficits in caring for patients and families. Various groups have defined palliative care in diverse but related ways. Each of the proposed definitions has in common the focus

on **relieving suffering** and **improving quality of life**.

The Institute of Medicine defines palliative care in this fashion: *“Palliative care seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure ... Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs ... It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them.”*

The World Health Organization (WHO) defines palliative care as: *“The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in*

conjunction with anti-cancer treatment.”

It goes on to expand and explain with these six points:

- Affirms life and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of care, fostering opportunities to grow
- Offers an interdisciplinary team to help patients live as actively as possible until death
- Offers a support system for the family during the patient’s illness and their own bereavement.

This is the aim **of creating** “the Patient support and Palliative care Group” affiliated to the Lebanese Cancer Society; the following citation summarizes the objectives of this Group: “We can have limits for **CURE** but there is no limit for **CARE**”.