

Core Curriculum for the Hospice and Palliative Nursing Assistant

Editor:

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CHAPTER 1 OVERVIEW OF HOSPICE AND PALLIATIVE NURSING ASSISTANT PRACTICE

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"What I do you cannot do; but what you do, I cannot do. The needs are great, and none of us, including me, ever do great things. But we can all do small things, with great love, and together we can do something wonderful."

Mother Teresa, 1910-1997

I. Introduction to Care at the End of Life^{1,2}

- A. The end of life (EOL) living and dying well
 - 1. The end of life
 - a) Final phase of life not defined by a time frame, such as six months
 - b) Natural part of life
 - c) There is an opportunity for personal growth during the process of dying; physical health declines, but many people can experience emotional healing and a sense of peace at the EOL
 - d) Profoundly personal experience
 - 2. Dying well
 - a) A "good death" is
 - Free from avoidable distress and suffering
 - Reflects patients' and families' goals and values ii.
 - iii. Should occur in all care settings, including home, hospital, long-term care facility, prisons
 - b) Dying well is a goal that is not always reached because
 - American society often avoids talking about death and isolates dying people
 - Hospice and palliative care services are not always available to patients and families
 - Many healthcare providers, including nurses, physicians, nursing assistants, do not know how to provide hospice and palliative care
 - iv. Some people do not prepare for death even when seriously ill because they think (wrongly) that a cure is always possible with high technology healthcare
 - v. Payment for healthcare services focuses on therapies aimed to cure diseases rather than help people live better with chronic illnesses

Dying is a natural part of life.

- vi. Comfort care is not standard in all settings because the major goals of treatment and expertise of care providers differs across settings; e.g., focus in acute care often is curing diseases and saving lives; focus in nursing home often is rehabilitation
- B. History of care at the end of life^{1,2,3}
 - 1. Focus on dying well has developed over the last 10-20 years
 - 2. Before the 1900s
 - a) Medicine could not cure most diseases
 - b) Physicians' job was to bring comfort and manage symptoms as much as possible
 - c) Death usually occurred at home
 - 3. Early to mid-1900s
 - a) Improved living and working conditions meant that many accidents and diseases were prevented
 - b) Treatment advances, such as the discovery of antibiotics, enabled people to live longer
 - c) Focus of medicine shifted to curing diseases
 - d) Death became a "failure" of medicine to cure the disease
 - e) Most deaths shifted from home setting and occurred in hospitals and other facilities
 - 4. 1990s to present
 - a) Focus still is very much on curing and technological advances
 - b) Despite these advances, people realize that
 - i. Not all diseases can be cured
 - ii. Death is still a reality
 - iii. More people are living longer with chronic diseases that decrease a person's quality of life
 - c) Studies done in the early 1990s showed that people often received care that kept them alive, but caused great suffering at the EOL; people questioned the focus on high-tech hospital care for patients with incurable illnesses³
 - d) Because of these studies, patients are taking a more active role in deciding what happens to them at the end of their lives; many people are choosing comfort care rather than high-tech intensive care when they have a disease that cannot be cured
 - e) In the future, people will continue to live longer, and more people will live with chronic diseases that cause disability
 - f) Healthcare needs to adjust and provide high-quality care for
 - i. Helping people live as well as they can with chronic, life-limiting diseases
 - ii. Helping people with advanced disease cope with the dying process earlier in the illness experience⁴