急重症安寧療護對社會及醫學倫理的實證基礎

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Concept revolution in medical care

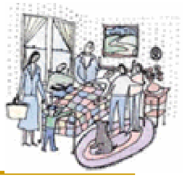
- Post-World War II scientific advances in health care and medical education created an almost exclusive focus on organ systems, disease states and injury-related models of care.
- Due to technological advances and major public health initiatives during this era, life expectancy grew considerably, and cure became an expectation.
- The age-old concern for the patient’s suffering and the quality of his or her life, a staple of medical practice and the ethos of medicine throughout history, seemed eclipsed by the focus on medical technology.
- Dying became a medical event, usually in a hospital, and often accompanied by significant pain and isolation.

Statistical data

- More than 50 percent of adult and 85 percent of pediatric deaths occur in hospitals in USA.
- Data from numerous studies demonstrate
  - high degrees of symptom distress across all age groups in hospitalized and nursing home patients;
  - high use of burdensome nonbeneficial technologies among the seriously ill; (27)
  - caregiver burden on families; (21) and
  - problems with communication between these patients, their families and their treating physicians about the goals of care and the medical decisions (13)
- The hospice movement give patients an alternative approach to high-technology, hospital-based medicine, and elect, instead, to pursue a course of palliative care.

The Medicare hospice benefit

- Under current Medicare/Medicaid guidelines, hospice care is covered for beneficiaries of these programs who are certified by their physician as likely to die within six months if the disease follows its usual course, and who are willing to give up insurance coverage for medical treatments of the terminal illness that are focused on cure or on prolongation of life.



The Medicare hospice benefit

- Once the hospice benefit has been accessed, patients and families may receive comprehensive services across all settings of care from an interdisciplinary team, although the great majority of hospice care is delivered at home.
- Medicare/Medicaid and most commercial insurances pay for medications and equipment related to the terminal illness, as well as practical, psychosocial, respite and bereavement support for caregivers. (1, 4)

People's response to hospice care

- The goals of hospice programs are to create increased opportunity for death at home, to focus on the symptom-control and psychological and spiritual issues that are paramount for persons in the terminal phases of an illness, and to provide bereavement support for their families.
- Since 1974, over 7 million patients and their families have received end-of-life care at home as well as in nursing homes and hospitals through hospice programs, with escalating use in recent years. (1)
- Surveys in the United States have consistently demonstrated a high rate of satisfaction with hospice services. (22)

PCS is more than hospice care

- In the past eight to ten years, physicians, nurses and other health care professionals in universities and teaching institutions have championed palliative care efforts to improve care for those seriously ill patients who do not meet hospice eligibility criteria or choose not to elect hospice care. These services, have been collectively termed “palliative care services.” They may be independent of hospice services or contractually related to hospices.
- Hospice care is completely appropriate at the end of life, but palliative care, in one form or another, is indicated, throughout all phases of life, whenever there are significant burdens from illness or trauma.
- The values that underlie palliative care—namely holistic outlooks, case management and attention to the patient’s quality of life and personhood—are values that must be integrated into the health care system.

Palliative care's place in the course of illness

- patient-centered model of interdisciplinary team care
- Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth.
- Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs and culture(s).
    - (From NATIONAL CONSENSUS PROJECT)

Shared philosophy and primary clinical characteristics of hospice care and PCS

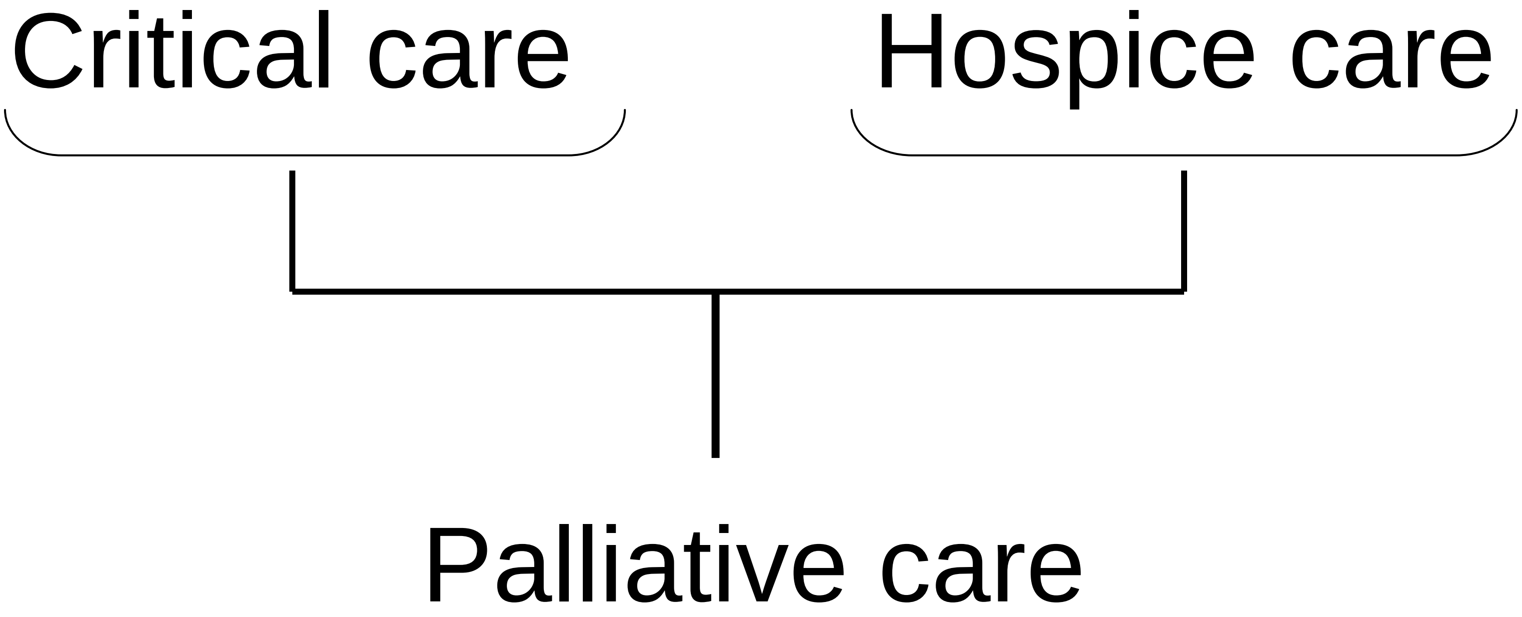
- Acknowledge the patient and their family as the unit of care, and value reduction of caregiver mortality and morbidity by actively reducing the physical and emotional burden associated with caregiving and grief.
  - Rely on interdisciplinary assessment, treatment and evaluation.
  - Energetically respond to the consequences of illness facing the patient and family, including:
    - Managing symptoms.
    - Providing practical guidance and support of care.
    - Offering anticipatory counseling/crisis prevention/critical decision support.
    - Recognizing the need for health promotion, even in the face of physical decline.
  - Incorporate a human development perspective with respect to life-altering illness.

Prefer PCS to Hospice

- As of 2002, 41 percent of hospices are delivering palliative care services outside the Medicare Hospice Benefit, and another 19 percent are planning such services in order to increase access to palliative care to patients who are ineligible for or unwilling to enter hospice programs.
- Data suggest that palliative care programs in a range of care settings (24) result in marked increases in the number of appropriate and timely referrals to hospice.

The Need for Expansion of Palliative Care Services

- a high prevalence of undertreated pain and other distressing symptoms among seriously ill patients of all ages and in all stages of illness. (13)
- high family caregiver burden, as well as increased morbidity and mortality for the family members of patients with chronic and life-threatening illness. (21)
- patients' top priorities are to be free of physical and psychological distress; to have some control over decisions about their health care; to avoid death-prolonging treatments; and to improve relationships with and reduce burden on their families. (8)
- The evidence demonstrate the ability of palliative care to help patients achieve these goals. (22)
- financial benefits (23,24)

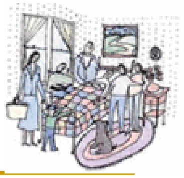


Critical care

Hospice care

Palliative care

Access to hospice programs should not be influenced by the availability of life-prolonging therapies or the patient’s desire to pursue these approaches, since many, if not most, patients wish to continue life-prolonging treatments as long as the treatment benefits outweigh the burdens.

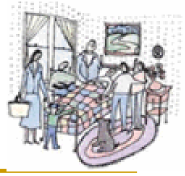


Palliative Service Care Movement

There is reason to be optimistic about improving access to palliative care services. As of 2002, more than 25 percent of academic medical centers and well over 950 hospitals (about 20 percent of all hospitals in the U.S.) indicate that they provide access to a palliative care program, including hospice. Additionally, nearly a third of the 3,200 U.S. hospices are hospital-based. In the last seven years, more than 1,200 physicians (including 18 pediatricians) have been certified as subspecialists by the American Board of Hospice and Palliative Medicine (www.abhpm.org) and approximately 7,000 registered nurses, 43 advanced practice nurses, and nearly 1,000 nursing assistants are certified in palliative care (www.nbchpn.org). Over the last three years, more than 1,000 physicians and 1,500 nurses have attended three-day-long educational conferences sponsored by Education for Physicians in End-of-Life Care (www.epec.net) and the adult and pediatric End-of-Life Nursing Education Consortium (www.aacn.nche.edu/elnec/). There are 42 postgraduate medical fellowship programs and two graduate nursing programs in palliative care across the country, and more are in planning stages (www.aahpm.org). In 2003, over 2,300 clinicians attended the NHPCO-HPNA Joint Clinical Conference to advance their skills in hospice and palliative care and more than 1,500 health professionals, representing over 600 hospitals and hospices, attended conferences sponsored by the Center to Advance Palliative Care which were aimed at helping health professionals and managers start and sustain palliative care programs (www.capc.org). Improvements in access to pediatric palliative care have evolved through demonstration models (www.chionline.org), development of pediatric palliative care curricular materials (www.ippcweb.org and www.nhpco.org), as well as increases in federal funding for both pediatric and adult palliative care research. Several programs targeted to nursing home professionals have also been developed (www.capc.org/specialpopulations). (30) Educational initiatives in social work include several fellowship training programs and Web-based curricula (www.swlda.org) and (www2.soros.org/death/swlda). (28)

The WHO defines palliative care (5)

- "An approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems.
- Palliative care:
  - Provides relief from pain and other distressing symptoms;
  - Affirms life and regards dying as a part of the life cycle;
  - Intends neither to hasten nor postpone death;
  - Offers a support system to help patients live as actively as possible until death;
  - Offers a support system to help the family cope during the patient's illness and in their own bereavement, including the needs of children;
  - Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
  - Will enhance the quality of life, and may also positively influence the course of a patient's illness."

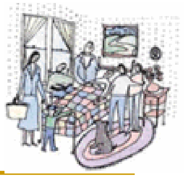


The goal of palliative care

- ***is to achieve the best possible quality of life through relief of suffering, control of symptoms and restoration of functional capacity while remaining sensitive to personal, cultural and religious values, beliefs and practices.***

Palliative care

- Palliative care is not meant to replace curative care, though it does assume a greater role as patients advance in the disease.
- Palliative care affirms life by supporting the patients' and families' goals for the future, including their hopes for cure or life-prolongation, as well as their hopes for peace and dignity throughout the course of illness, the dying process and death.



Core Elements of Palliative Care

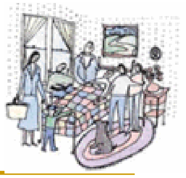
- Patient- and family-centered care:
- Timing of palliative care:
- Comprehensive care:
- Interdisciplinary team:
- Attention to relief of suffering:
- Communication skills:
- Skill in care of the dying and the bereaved:
- Continuity of care across settings:
- Equitable access:
- Quality improvement:

Quality improvement in PCS

- Timely—delivered to the right patient at the right time.
- Patient-centered—based on the goals and preferences of the patient and the family.
- Beneficial and/or effective—demonstrably influencing important patient outcomes or processes of care linked to desirable outcomes.
- Accessible and equitable—available to all who are in need and who could benefit.
- Knowledge- and evidence-based.
- Efficient and designed to meet the actual needs of the patient and not wasteful of resources.

Palliative care in Critical Care

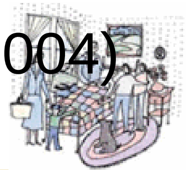
- Palliative care principles and guidelines encompass the physical, psychological, spiritual and practical burden of illness and focus patients’ and families’ needs, values and beliefs regarding health, illness and death, and take into consideration cultural, religious and ethnic backgrounds in the goals of care.



CLINICAL PRACTICE GUIDELINES FOR QUALITY PALLIATIVE CARE

- Domains of Quality Palliative Care
  - Structure and Processes;
  - Physical Aspects of Care;
  - Psychological and Psychiatric Aspects of Care;
  - Social Aspects of Care;
  - Spiritual, Religious and Existential Aspects of Care;
  - Cultural Aspects of Care;
  - Care of the Imminently Dying Patient; and
  - Ethical and Legal Aspects of Care

National Consensus Project (2004)

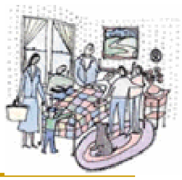


The Seven Domains of EOLC

- **These domains, quality indicators and interventions or behaviors were generated in a modified Delphi approach as described in the following article:**
  - Clarke EB, Curtis JR, Luce JM, Levy M, Nelson J, Solomon MZ, for the Robert Wood Johnson Foundation Critical Care End-of-Life Peer Workgroup Members. Quality indicators for end-of-life care in the intensive care unit. **Critical Care Medicine** 2003,
- The items under each domain represent potential suggestions for clinician and/or organizational interventions or behaviors that may improve the quality of end-of-life care in the ICU setting. Most of these interventions or behaviors have not been tested in randomized trials and the majority of them represent expert clinician opinion.

The seven domains

- **Domain 1 –**
  - **Patient and Family Centered Decision Making**
- **Domain 2 –**
  - **Communication within the Team and with Patients and Families**
- **Domain 3 –**
  - **Continuity of Care**
- **Domain 4 –**
  - **Emotional and Practical Support for Patients and Families**
- **Domain 5 –**
  - **Symptom Management and Comfort Care**
- **Domain 6 –**
  - **Spiritual Support for Patients and Families**
- **Domain 7 –**
  - **Emotional and Organizational Support for ICU Clinicians**



Domain 1 –

Patient and Family Centered Decision Making

- Recognize the patient and the family as the unit of care
- Assess the patient’s and family’s decision-making style and preferences:
- Address conflicts in decision making within the family and between staff and family:
- Assess together with appropriate clinical consultants, the patient’s capacity to participate in decision-making about treatment and document assessment.
- Initiate advance care planning with the patient and family:

Domain 1 – (continued)
Patient and Family Centered Decision Making

- Clarify and document the status of the patient's advance directive:
- Identify the health care proxy and surrogate decision-maker:
- Clarify and document resuscitation orders:
- Assure patients and families that decision-making by the health care team will incorporate their preferences.
- Follow ethical and legal guidelines for patients who lack both capacity and a surrogate decision-maker:

Domain 1 – (continued)
Patient and Family Centered Decision Making

- Establish and document clear, realistic and appropriate goals of care in consultation with the patient and family:
- Help the patient and family assess the benefits and burdens of alternative treatment choices as the patient condition changes.
- Forgo life-sustaining treatments in a way that ensures patient and family preferences are elicited and respected:

Domain 2 –
Communication within the Team and with Patients and Families

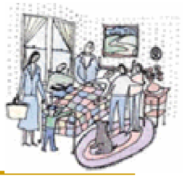
- Meet as an interdisciplinary team to discuss the patient’s condition, clarify goals of treatment and identify the patient’s and family’s needs and preferences
- Address conflicts among the clinical team prior to meeting with the patient and/or family
- Utilize expert clinical, ethical and spiritual consultants when appropriate:
- Recognize the adaptations in communication strategy required for patients and families according to the chronic versus acute nature of illness, cultural and spiritual differences and other influences:

Domain 2 – continued
Communication within the Team and with Patients and Families

- Meet with the patient and/or family on a regular basis to review patient’s status and answer questions
- Communicate all information to patients and families, including distressing news, in a clear, sensitive, unhurried manner and in an appropriate setting:
- Clarify the patient’s and family’s understanding of the patient’s condition and goals of care at the beginning and end of each meeting
- Designate primary clinical liaison(s) who will communicate with the family daily
- Identify a family member who will serve as the contact person for the family
- Prepare the patient and family for the dying process

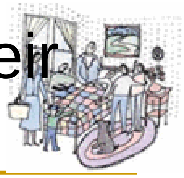
Domain 3 - Continuity of Care

- Maximize Continuity of care across clinicians, consultant and settings
- Orient new clinicians regarding the patient and family status
- Prepare the patient and/or family for a change of clinician(s) and introduce new clinicians.



Domain 4 –
Emotional and Practical Support for Patients and Families

- Elicit and attend to the needs of the dying person and his/her family.
- Distribute written material (booklet) for families that includes: orientation to the ICU environment and open visitation guidelines; listings of financial consultation services; and bereavement programs and resources:
- Facilitate strengthening of patient-family relationships and communication:
- Maximize privacy for the patient and family
- Value and support the patient's and family's cultural traditions:
- Arrange for social support for dying patients without family or friends.
- Support the family through the patient's death and their bereavement:



Domain 5 –
Symptom Management and Comfort Care

- Emphasize the comprehensive comfort care that will be provided to the patient rather than focus on the removal of life-sustaining treatments:
- Institute and use uniform quantitative symptom assessment scales appropriate for communicative and non-communicative patients on a routine basis.
- Standardize and follow best clinical practices for symptom management.
- Use non-pharmacologic as well as pharmacologic measures to maximize comfort as appropriate and desired by the patient and family.

Domain 5 – contined
Symptom Management and Comfort Care

- Reassess and document symptoms following interventions.
- Know and follow best clinical practices for withdrawing life-sustaining treatments to avoid patient and family distress.
- Eliminate unnecessary tests and procedures (lab work, weights, routine vital signs etc.), and only maintain IVs for symptom management in situations where life-support is being withdrawn.
- Minimize noxious stimuli (monitors, strong lights, etc.).
- Attend to the patient’s appearance and hygiene.
- Ensure family and/or clinician presence so the patient is not dying alone:

Domain 6 –
Spiritual Support for Patients and Families

- Assess and document spiritual needs of the patient and family on an on-going basis.
- Encourage access to spiritual resources.
- Elicit and facilitate spiritual and cultural practices which the patient and family find comforting.

Domain 7 –
Emotional and Organizational Support for ICU Clinicians

- Support health care team colleagues caring for dying patients
- Adjust nursing staffing and medical rotation schedules to maximize continuity of care providers for the dying patient.
- Communicate regularly with interdisciplinary team regarding goals of care:
- Establish a staff support group, based on the input and needs of ICU staff and experienced group facilitators, and integrate meeting times into the routine of the ICU:
- Enlist palliative care experts, pastoral care representatives and other consultants to teach and model aspects of EOLC:
- Facilitate rituals for the staff to mark the death of patients.

Five wishes

- Five wishes of the patient, including

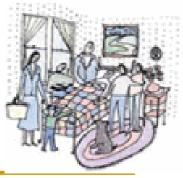
1) which surrogate to choose,

2) which treatment to accept,

3) how comfortable you want to be,

4) how you want people to treat you, and

5) what you want loved ones to know.



Thank you for your attention

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