

Module # 10: Introduction to Palliative & Hospice Care

Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 10: Introduction to Palliative & Hospice Care

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I. Overview

While over 2 million deaths are expected annually in the United States, millions more people are living, often for many years, with chronic diseases and other serious illnesses that significantly affect their quality of life and ability to function. Most older adults will develop one or more chronic illnesses with which they may live for many years, often with physical and psychological symptom distress and progressive functional dependence and frailty. It is widely acknowledged that the care of these individuals is in need of improvement. There is now abundant evidence that the quality of life during these advanced stages of disease is often poor, characterized by inadequately treated physical, psychosocial, and spiritual distress; fragmented care systems, poor communication between health care providers, patients and families, and enormous strain on family caregiver and support systems.

Despite these demographic trends pointing to the critical need for services in palliative care for the older population, this is an area with a significant lack of training and education. This module addresses this need with an introduction to several key practices and principles of palliative care.

II. Learning Objectives

1. Discuss the demographics related to dying in America.
2. Discuss the results of the SUPPORT study and implications for palliative care.
3. Conceptualize a good death.
4. Identify the goals of palliative care.
5. Articulate the goals, precepts, and importance of the National Consensus Project Guidelines.
6. Discuss the palliative care domains identified by the National Consensus Project Guidelines.
7. Identify the expected outcomes of the National Consensus Project Guidelines.
8. Describe the criteria for JCAHO certification in palliative care.
9. Identify the site of delivery for palliative care.
10. Discuss barriers to end-of-life care.
11. Discuss Hospice care, including the benefits, barriers, standards, and Hospice eligibility under Medicare.
12. Discuss the role of members of the interdisciplinary palliative care team and the value of an interdisciplinary approach.
13. Identify the factors that signal the need for a palliative care consult.

14. Discuss causes of inadequate pain management and principles.
15. Assess the spiritual/cultural needs of patients and families in palliative care.
16. Discuss critical aspects related to the care of the dying.

III. Demographics Of Dying In The U.S. ¹

A. The Current State of Dying

1. Americans are living longer than ever before.
2. The life expectancy at age 65 is 18.1 years. The life expectancy of those aged 85 is 6.5 years.
3. Women in both age groups tend to live longer than men. The life expectancy of a woman age 65 is 19.4 years, 3 years higher than the 16.4 years expected for a man. At 85, women have a life expectancy of 6.9 years, while men have a life expectancy of 5.7 years.
4. The two leading causes of death among those over 65 are heart disease and malignant neoplasms.
5. Chronic illnesses plague those over age 65. Over 30% report suffering from heart disease, 50% suffer from hypertension, and 21% suffer from some form of cancer.
6. Symptoms at the End of Life: Cancer vs. Other Causes of Death.

B. Sites of Death ²

- | | |
|------------------|-----|
| 1. Hospitals | 56% |
| 2. Nursing homes | 19% |
| 3. Home | 21% |
| 4. Other | 4% |

IV. The SUPPORT Study: Evidence Of The Need For Palliative Care

- A. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT): a multicenter controlled trial to improve the care of 9,000 patients with life-threatening illnesses. The study was funded by RWJ. Phase I was “How people die in hospitals” and Phase II, “RCT of nurse-based intervention.” 2,500 subjects were in each group. The median age of the patients (total patients in study: 9,105) was 65, with 56% on Medicare. 44% were female. ³
1. Phase I of SUPPORT was to determine objective measures of quality of death: presence and timing of written DNR, MD awareness of DNR preferences, number of “undesirable” days, pain levels, and costs of care. Phase I found the following:

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- 46% of DNR orders were written within the last 2 days of life, suggesting little advance planning in terminal illness.
- Physicians did not always understand their patients. For example, 53% of physicians did not understand that a patient wanted to avoid CPR.
- 38% of patients experienced 10 or more days in the ICU, in a coma, or on a ventilator.
- Half of patients (50%) experienced moderate or severe pain at least ½ of the time within their last few days.
- Seriously-ill patients' families were impacted as:

Needed large amount of family caregiving	34%
Lost most family savings	31%
Lost major source of income	29%
Major life change for family member	20%
Other family illness from stress	12%
At least one of the above	55%

2. Phase II of SUPPORT, conducted from 1992-1994, demonstrated the need for hospitals and health systems to pursue a higher standard for end-of-life care- a standard that includes helping patients learn how to live well while dying; focusing on the patient and family, not just the disease; and working with the patient and family to create a plan for dying.

V. A Good Death

A. Criteria for a Good Death⁴

1. Relatively free of pain
2. Suffering kept to a minimum
3. Social and emotional needs are met
4. Maintaining independence and function
5. Resolving personal and social conflicts
6. Free to choose and relinquish control over various aspects of life

B. Goals of care

1. Treat the disease
2. Prolong the patient's life while managing symptoms
3. Restore or maintain function
4. Maintain quality of life
5. Preserve control
6. Comfort and support the patient and family

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7. Avoid needless suffering in order to permit experiences that will have positive meaning

C. Goals May Change Near the End of Life

1. Some goals may take priority over others
2. The shift in the focus of care is:
 - gradual
 - an expected part of the continuum of medical care
3. Review goals with any change in:
 - health/functional status (e.g. advancing illness)
 - setting of care
 - treatment preferences

VI. National Consensus Project Guidelines For Quality Palliative Care

A. Goal of Palliative Care

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients of all ages and their families experiencing advanced chronic or life-threatening illnesses in all health care settings.⁵

B. Precepts Regarding Palliative Care

1. Palliative care is offered from the time of diagnosis with serious, chronic, debilitating, or life-threatening illness through the full course of illness and into the bereavement period for families.
2. Palliative care is holistic care that focuses on the physical, psychosocial, cultural, and spiritual needs of patients and their families.
3. Palliative Care ensures:
 - a. Physical comfort through state-of-the art, comprehensive management of pain and symptoms.
 - b. Practical needs are addressed and coordinated.
 - c. Psychosocial and spiritual distress is managed.
 - d. Patients and families receive the information needed to understand their condition and treatment options.
 - e. Patient and family values and decisions are respected and honored.
 - f. Coordination of care and communication across health care settings.
 - g. Patient and family are prepared for the dying process and death as possible, when it is anticipated.
 - h. Hospice options are explored.
 - i. Opportunities are available for growth and resolution.
 - j. Bereavement support is available.⁵

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C. Palliative Care Continuum

1. Palliative care can be delivered concurrently with life prolonging care or as the main focus of care.
2. Close coordination and partnership between palliative care and hospice programs are critical to achieving continuity of palliative care throughout the illness/dying trajectory and across the continuum of care settings.
3. Palliative Care is both a general approach to patient care routinely integrated with disease-modifying therapies, as well as a growing practice specialty for highly trained specialist physicians, nurses, social workers, chaplains, and others who typically work on interdisciplinary palliative care teams.⁵

D. The Importance of Palliative Care

1. There is an overall aging of the population with an increase in chronic debilitating or life-threatening conditions. The nation is about to experience a great demographic shock. Between 2010 and 2030 the 65+ population will rise over 70 percent.
2. Palliative Care involves persons of any age with acute, serious, chronic, or life-threatening illness and a broad range of diagnostic categories.
3. Patients are suffering needlessly.
4. Patients need support in navigating the health system.
5. Policy makers need effective solutions.
6. Health care settings are challenged to deliver efficient and effective management of long-term advanced illness.
7. Clinicians need support and expertise for treating this growing population.⁵

E. The Relationship Between Hospice and Palliative Care

1. Hospice has created “gold standard” of care.
2. Hospices are successfully expanding services to provide palliative care to patients in a variety of settings earlier in the course of illness.
3. Leading hospitals and long-term care facilities have started palliative care programs.
4. Hospital-hospice partnerships are being created.
5. Palliative care represents the success of the hospice movement in influencing the rest of the health care system.⁵

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- F. National Consensus Project (NCP) (2005) Mission
1. To create a set of voluntary clinical practice guidelines to promote consistent high quality palliative care.
 2. To guide the development and structure of new and existing palliative care programs.
 3. Establish accepted definitions, essential elements, and best practices for palliative care.
 4. Foster continuity of care across health care settings.⁵
- G. National Consensus Project Goals
1. Stimulate and guide the development of new and existing palliative care programs across care settings.
 2. Promote care of consistent, high quality.
 3. In the absence of organized palliative care programs or specialists, guide clinicians to incorporate vital aspects of palliative care into their practice to improve care for their sickest patients over the course of their illnesses.
 4. Build national consensus concerning the definition, essential elements, and best practices of palliative care through an open and inclusive process that includes the array of professionals, providers, and consumers involved in and affected by palliative care.
 5. Broadly disseminate the clinical practice guidelines to enable existing and future programs to better define their program organization, resource requirements, and performance measures.
 6. Foster continuity of palliative care by expansion of access to care and coordination across settings through hospice and other care management programs.
 7. Promote recognition, stable reimbursement structures, and accreditation initiatives.⁵
- H. The National Consensus Project Process
1. Resulted from a national leadership conference in December 2001 initiated by the Center to Advance Palliative Care.
 2. Created a national consensus process for creating and disseminating a consensus document with potential endorsement of both the palliative and hospice communities and those involved with policy, regulatory, and fiscal management of health care.
 3. Created a process that was inclusive, interdisciplinary, transparent, and meaningful to those who will be affected.⁵

The National Consensus Project Membership:

- a. Steering Committee – 20 members develop draft document
- b. Advisory Committee – 100 nationally recognized leaders across a variety of health care settings review and revise

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- c. Liaison Organizations – 50 organizations with major responsibility for health care of patients with life-threatening illness endorse and disseminate the standards
 4. Created an NCP grant proposal and raised \$200,000 from a range of sources to support the administrative requirements.
 5. Secured professional and fiscal commitments from the consortium organizations.
 6. Maintained regulation communication between the steering committee, NCP advisory committee, and potential funders.
 7. Developed the National Clinical Practice Guidelines based on scientific evidence, clinical experience, and expert opinion.
 8. Created a communication plan in collaboration with a professional relations firm and disseminated the guidelines in April 2005.
- I. National Consensus Project Assumptions
1. The guidelines represent goals that palliative care programs should strive to attain as opposed to minimal practices.
 2. Health care quality standards will be followed such as safety, effective leadership, medical record keeping, and error reduction.
 3. The guidelines assume codes of ethics.
 4. The guidelines will evolve as professional practice, the evidence-base, and health care system change over time.
 5. Guidelines are peer-defined; established through a consensus process with a broad range of palliative care professionals.
 6. Specialty care involves professionals with palliative care qualifications through professional credentials and programmatic accreditation.
 7. Continuing professional education.
 8. Applicability of guidelines to promote integration and application of the principles, philosophy, and practices of palliative care across the continuum of care and health care settings.⁵
- J. The 8 Clinical Practice Domains for Palliative Care⁵

Domain 1: Structure and Process of Care

1. Plan of care is based on a comprehensive interdisciplinary assessment of patient and family.
2. Addresses both identified and expressed needs of patient and family.
3. An interdisciplinary team provides services consistent with the plan of care.
4. Team is committed to quality improvement.
5. Support for education and training of professionals.
6. Emotional impact of work on team members is addressed.
7. Team has relationship with hospices.
8. The physical environment is considered in providing care.⁵

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Domain 2: Physical

1. Pain, other symptoms, and treatment side effects are managed using best practices.
2. Team documents and communicates treatment alternatives, permitting patient/family to make informed choices.
3. Family is educated and supported to provide safe/appropriate comfort measures to patient.⁵

Domain 3: Psychological and Psychiatric

1. Psychological and psychiatric issues are assessed and managed based on best available evidence.
2. Team employs pharmacologic, non-pharmacologic, and complementary therapies as appropriate.
3. Grief and bereavement program is available to patients and families.⁵

Domain 4: Social

1. Assessment (e.g. Family structure, relationships, medical decision making, finances, sexuality, caregiver availability, access to medications, and equipment).
2. Individualized, comprehensive care plan alleviates caregiver burden and promotes well-being.⁵

Domain 5: Spiritual, Religious and Existential

1. Assesses and addresses spiritual concerns.
2. Recognizes and respects religious beliefs- provides religious support.
3. Makes connections with community and spiritual/religious groups or individuals as desired by patient/family.⁵

Domain 6: Cultural

1. Assesses and aims to meet the culture-specific needs of patients and families.
2. Respects and accommodates range of language, dietary, habitual, and ritual practices of patients and families.
3. Team has access to/uses translation resources.
4. Recruitment and hiring practices reflect cultural diversity of community.⁵

Domain 7: The Imminently Dying Patient

1. Team recognizes imminence of death and provides appropriate care to patient/families.

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2. As patients decline, team introduces hospice referral option.
3. Team educates family on signs/symptoms of approaching death in a developmentally, age, and culturally appropriate manner.⁵

Domain 8: Ethics and Law

1. Patient's goals, preferences, and choices are respected and form basis for plan of care.
2. Team is aware of and addresses complex ethical issues.
3. Team is knowledgeable about relevant federal and state statutes and regulations.⁵

K. Expected Outcomes of the National Clinical Practice Guidelines⁵

A. Hospitals will:

1. Develop quality programs;
2. Have increased efficiency: appropriate use of resources, decreased hospital and ICU stays, lower costs;
3. Better clinical outcomes: relieves pain and distressing symptoms in all stages of treatment;
4. Strengthened patient satisfaction: patients get comfort care without forgoing other treatment;
5. Improved staff retention and morale: supports doctors/nurses in care of complex patients;
6. Meet JCAHO Hospital Accreditation Standards.

B. Nursing Homes will:

1. Develop roadmaps for caring for patients with chronic illness;
2. Have improved patient outcomes in accord with regulations;
3. Will meet patient and family needs;
4. Strengthen patient satisfaction: patients get comfort care without forgoing other treatment;
5. Improve staff retention and morale: supports doctors/nurses in care of complex patients.

C. Health Care Professionals will:

1. Provide optimal, evidence-based care to the most complex, sick patients without significant workload burden.

D. Policymakers will:

1. Be able to strengthen a health system that serves our sickest patients;
2. More appropriately use of financial resources to improve care while lowering costs;

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3. Ensure that all patients and their families, your constituents, receive a uniform and appropriate level of care.

E. Patients and the Public will

1. Receive expert pain and/or symptom relief and end needless suffering;
2. Understand their right to the best quality care;
3. Receive assistance in navigating the medical system and choosing health care providers.

L. JCAHO Certification in Palliative Care

1. Palliative Care Program Certification is a two-year award.
2. Successful programs will be acknowledged on the JCAHO website.
3. Palliative Care Certification can be achieved with or without concomitant JCAHO Accreditation.
4. Accreditation is an organization wide award.
5. Certification for Palliative Care is special recognition of excellence in the provision of palliative care services.⁵

VII. Delivery Of Palliative Care

A. Hospital-Based

1. Primary care
2. Consultation
3. Inpatient Unit

B. Nursing Home

C. Hospice

1. Home hospice
2. Hospital inpatient
3. Hospice inpatient

VIII. Barriers To End-Of-Life Care⁶

- A. Areas in which barriers usually reside include institutional culture, structures, policies, regulations, reimbursements, and individual attitudes.
- B. 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.
- C. Fears of addiction, exaggerated risks of adverse effects, and restrictive legislation have resulted in inadequate control of symptoms.

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- D. Discomfort with 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 to decline or withdraw treatment have led to frequent misunderstanding and excessive futile intervention.
- E. Personal fears, fantasies, worries, and lack of confidence have prompted many physicians to avoid dealing with patients who are dying.

IX. Hospice

- A. What is Hospice?⁷
 - 1. A reimbursement benefit for patients who have a limited prognosis or life expectancy.
 - 2. Primarily community-based
 - 3. Care for severely ill patients and their families
 - 4. Team of professionals and trained volunteers
 - 5. Focus is on care, not cure
 - 6. Goals:
 - Relief of pain and other symptoms
 - Psychosocial support
- B. In order to be most effective, hospice strives to administer care to all patients with any life-threatening diagnosis at any time during their illness when they need symptom control or have supportive care needs and are prepared to accept care.
- C. As of 1995, about 17% of patients died while under hospice care.
- D. The term "hospice" can refer to any one of the following, which often times is a source of confusion:
 - 1. A site of care for the dying.
 - 2. An organization that provides care in a variety of settings but is usually focused on the patient's home. Hospice agencies started in the US in the late 1970s in order to help families care for patients with advanced life-threatening illnesses.
 - 3. An approach to care that is integrated across all health care settings and practices.
 - 4. A benefit available to Medicare beneficiaries and subject to the rules and regulations promulgated by HCFA to govern that federal program.
- E. Hospice care provides:
 - 1. Patient control over decisions about care
 - 2. Family involvement
 - 3. Specialized services

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- Pharmaceuticals and home supplies/equipment
 - Pastoral support
 - Grief counseling
 - Volunteer support
4. Option for patient to die at home
- F. Conditions for Hospice Eligibility under Medicare:
1. Limited life expectancy (generally 6 months or less)- certified by physician.
 2. Patient chooses hospice benefits rather than standard Medicare (patient may choose to stop hospice care and revert to cure-oriented care at any time).
 3. Care provided by Medicare-certified hospice program.
 4. A physician to direct care.
 5. Available/able/willing caregiver at home.
- G. The standards by which hospice are regulated may also be useful when applied to palliative care. Palliative care:
1. Attempts to expand rather than limit access to and delivery of care.
 2. Provides patients and their families with adequate information. They should be able to make informed choices and participate in choice of settings and interventions.
 3. Along with the communities, hospitals and physicians develop programs to provide patients and their families with symptom management, mental and spiritual health, and social support.
 4. Provides grief and bereavement support for the family.
 5. Provides continuity between care settings. Sometimes transfer is deemed necessary and continuity of providers between settings should be available.
 6. Ensures that incoming professionals are well educated in their roles in palliative care by means of evaluation, research, and education.

X. Comparison Of Hospice And Palliative Care

Hospice

- Prognosis of 6 months or less
- Focus on comfort care
- Medicare hospice benefits
- Volunteers integral and required aspect of the program
- Interdisciplinary care

Palliative Care

- Any time during illness
- May be combined with curative care
- Interdisciplinary care
- Independent of payer

XI. Interdisciplinary Teams In Palliative Care ⁸

- A. The Interdisciplinary Team members may consist of the following disciplines:
1. **Physician:** hospice and primary care attending.
 2. **Nurse:** coordination drives most patient services and care such as assessment, evaluate needs for supplies and equipment, therapy, counseling, and spiritual and emotional dimensions of quality of life.
 3. **Social Worker:** review plan of care with team and initial psychosocial assessment. Identify problem list; role in bereavement process.
 4. **Counselor/Clergy:** focus on spiritual concerns, grief, and loss.
 5. **Volunteers:** hands of care-work in office, public relations, and fundraising.
 6. **Home Health Aide:** provides physical care.
- B. Factors that may signal the need for a team approach:
1. The presence of advancing disease not responding to disease-directed therapies.
 2. Poorly controlled or multiple symptoms.
 3. Deteriorating functional status.
 4. Increasing debility or need for nursing care.
 5. Increasing distress-difficulty coping physically, emotionally, or financially.
 6. Caregiver burden increased by poor control of symptoms, need for frequent medications, physical strain, interrupted sleep, confinement, and isolation.

XII. Identification Of Holistic Aspects Of Palliative Care

- A. Need for Pain Assessment and Management
1. Research indicates that under treatment of pain:
 - a. For 597 ambulatory cancer patients, pain was greatest in women from age 63-69 and in men age 70-90. ⁹
 - b. For minority patients with cancer, Hispanics reported greatest pain (72%); blacks were second highest (59%), whites were the lowest (49%). ¹⁰

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- c. Of ambulatory NYC AIDS patients, approximately 84% expressed need vs. approximately 49% expressed by patients with cancer. ¹¹
2. Causes of Inadequate Pain Management ¹²
 - a. Clinician-related factors:
 - Lack of pain assessment skills
 - Lack of knowledge of pain management
 - Inappropriate avoidance of opioid
 - Overestimation of risk of addiction
 - Overestimation of risk of tolerance
 - Concern about managing side effects
 - Concern about regulation of controlled drugs
 - b. Patient-related factors:
 - Problems reporting pain due to desire to focus on cure, stoicism, desire to please staff, fear of suppressing pain
 - Reluctance to take opioid due to fear of addiction, fear of tolerance, fear of side effects
 - Poor compliance
 - c. Health system factors:
 - Focus on life prolongation and cure
 - Low priority given to pain/symptom control
 - Unavailability of opioids
 - Lack of access to palliative care expertise
 - Inadequate insurance coverage
3. Pain Assessment Principles ¹³
 - a. Ask the patient and believe his/her complaint.
 - b. Develop a systematic approach to assessment using a validated pain scale and including:
 - Pain history (location, duration, intensity, quality, relieving/exacerbating factors, associated factors (i.e. nausea, weakness), changes in functional status, and the meaning of pain.
 - Physical examination, including neurological exam if indicated.
 - Diagnostic procedures depending on goals of care.

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- c. Reassess frequently
- B. Addressing Religious/Spiritual Needs ^{14,15}
1. Religiosity refers to the beliefs and practices of different religious faiths and an acceptance of their traditions.
 2. Spirituality is a broader concept than religiosity. It refers to:
 - the energy in the deepest core of the individual.
 - an integrating life force within that allows us to transcend our physical being.
 - whoever or whatever gives ultimate meaning and purpose in one's life.
 - the sense of connectedness with self, others, nature, and an ultimate being.
 3. Spirituality may be understood as non-material or metaphysical, hence pertaining to sacred things or the soul, or more broadly, the intellectual and moral aspects of life. Religion provides a set of core beliefs about life events and establishes an ethical foundation for clinical decision making.
 4. Okon ¹⁵ identified themes of an existentially/spiritually focused history as:
 - Meaning
 - Hopes, identity, continuity
 - Legacy
 - Trust, support, and caring relationships
 - Life review: Experience of pain and forgiveness or estrangement and reconciliation
 - Resilience and self-efficacy
 5. Tasks of religion and spirituality:
 - Confront one's finitude and vulnerability.
 - Uncover meaning, value, and dignity in illness and death.
 - Develop meaning, purpose, and connectedness to others.
 - Seek faith, hope, love, and forgiveness in the midst of fear and despair.
 - Engender serenity and transcendence, thereby buffering stress.
 6. Spiritual Needs of the Ill and Dying ¹⁶
 - a. The search for meaning of life and purpose of one's own existence through a review of life and its goals, values, and experiences.
 - b. The need to die appropriately or meaningfully in a way that is consistent with our self-identity.
 - c. Assurance that our life in some way will continue. Symbolic immortality through our children, creative works, theology, eternal nature, or community.

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7. Spiritual History addresses the following questions:¹⁷
 - F: Faith** – does religion or spirituality play an important part in your life? Do you consider yourself a religious or spiritual person?
 - I: Influence** – How does your religious faith or spirituality influence the way you think about your health or the way that you care for yourself?
 - C: Community** – Are you a part of a religious or spiritual community?
 - A: Address** – Would you like me to address your religious or spiritual issues or concerns with you?

 8. Symptoms of Spiritual Pain:¹⁴
 - a. Sorrow and grief
 - b. Isolation of self and others
 - c. Meaninglessness and emptiness
 - d. Fear and avoidance of the future
 - e. Hopelessness and despair
 - f. Anger and bitterness towards God

 9. Connecting Spirituality with Patients by:¹⁷
 - W: Welcome** – demonstrate acceptance and invite the patient to discuss issues of faith and belief.
 - E: Encouragement** – to continue healthy religious beliefs and practices.
 - B: Blessing** – express words of blessing in a faith sensitive manner such as “Blessings to you.”

 10. Implications for Caregivers Regarding Spiritual Care:
 - Explore their concerns in a non-judgmental and non-threatening way.
 - Enable the dying to strengthen their own meanings of death.
 - Support individuals’ needs for rituals (i.e. confession or communion, prayer, etc.).

 11. Accommodating Cultural Diversity:¹⁴
 - a. Know your own attitudes, beliefs, values, and cultural practices.
 - b. Listen for language patterns.
 - c. Gather information about distinctive practices, rituals, beliefs, and assumptions.
 - d. Find out who makes the decisions.
 - e. Identify their time orientation.
 - f. Ask “What can I do for you today?”
- C. Care of the Dying
1. Developmental Tasks of Dying:¹⁶
 - a. Experience love of self and others
 - b. The completion of relationships
 - c. The acceptance of finality of one’s life
 - d. The achievement of a new sense of self despite physical demise

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2. Guidelines for Communicating with a Dying Patient: ¹⁸
 - a. Deliver and interpret the technical information given to the patient – check out the patient’s perceptions of what is being told.
 - b. Facilitate meaningful discussions and ask questions to determine if they understand in a climate that is supportive.
 - c. Encourage patients and families to discuss alternatives and their consequences.
 - d. Recognize the values of the patient and family.
 - e. Do not undermine the patient’s right to determine his own fate.

3. Guidelines for Counseling: ¹⁹
 - a. Ensure that patient has as much control as possible – it is the patient’s life and death even if we disagree.
 - b. Provide a working team to provide a holistic plan of care.
 - c. Normalize feelings without minimizing them.
 - d. Ask what questions are on the patient’s mind.
 - e. Help patient communicate clearly and know what the patient is really asking by requesting clarification and use of reflection.
 - f. Acknowledge the difficulties of terminal illness – but do not confront the patient.
 - g. Make sure you are talking about the same issue.
 - h. Recognize the incongruities between your verbal and non-verbal communication.
 - i. Capitalize on the times the patient is willing to talk.

4. Completing Relationships ²⁰

The need to say:

 - I forgive you
 - Forgive me – I’m sorry
 - Thank you
 - I love you
 - Goodbye

5. Active Presence-ing
 - a. Staying with a dying patient – saying whenever you do die I am going to miss you. You really are a privilege to know. Is there anything else that you need or want?
 - b. Telling the person how much he/she is loved and how much he/she will be missed and to journey on knowing that he/she will always be loved.

XIII. Conclusion

“If medicine takes aim at death prevention, rather than at health and relief of suffering, if it regards every death as premature, as a failure of today’s medicine – but avoidable by tomorrow’s – then it is tacitly asserting that its true goal is bodily immortality . . . Physicians [and other health professionals] should try to keep their eyes on the main business, restoring and correcting what can be corrected and restored, always acknowledging that death will and must come, that health is a mortal good, and that as embodied beings we are fragile beings that must stop sooner or later, medicine or no medicine.”²¹

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