


Palliative and Hospice Care
Part 1

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Learning Objectives

1. Be able to define Palliative Care
2. Be able to explain what are the goals of Palliative Care
3. Be able to discuss who all is involved in Palliative Care
4. Be able to identify discuss the diversity of pain and suffering in individuals
5. Be bale to discuss the assessment of a Plan of care for a person receiving Palliative care




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Palliative Care

- Palliative care aims to relieve suffering in all stages of disease and does not have to be limited to end-of-life care.
- Palliative care may be provided along with curative or life-prolonging treatments. Palliative care also extends to the family's or loved ones' bereavement period.



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Palliative Care

- In addition to symptom management, other objectives of comprehensive palliative support include establishing goals of care that are in keeping with the patient's values and preferences;
- Consistent and sustained communication between the patient and all those involved in their care;
- Psychosocial, spiritual, and practical support both to patients and their family or other informal caregivers; and coordination across sites of care.

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Palliative CARE

- Given the scope of palliative care, a unique approach to clinical evaluation is required. Although a comprehensive palliative assessment includes all the standard elements of a medical history and relevant aspects of the physical examination, it also extends beyond the traditional domains.

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Total Pain

- Dame Cicely Saunders, the founder of modern hospice and palliative care, introduced the term "total pain"
- Dr. Saunders observed that her patient's pain included not only physical but also "...emotional and mental suffering, her social problems, and her spiritual need for security and meaning"

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Total Pain

- Accordingly, the concept of "total pain," which provides a defining framework for patient assessment in palliative care
 - Refers to the complex mechanisms and manifestations of suffering
 - Includes physical, emotional, socioeconomic, and spiritual components

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Diversity of Individual experience

- A person's pain or malaise, their body image, the meaning they have of their illness, their desires, their relationships, and their values or spiritual beliefs all contribute to their experience of illness and suffering [
- A precise, clinical taxonomy of suffering is not available because total pain is constructed in a highly individual way
- There is no single, good way of facing a serious illness; likewise, there is no single definition of what constitutes a "good" death

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Diversity of Experience

- Given the diversity of the individual experience of suffering, the specific palliative care needs and goals of individual patients are challenging to identify a priori or derive from population-based studies [as extent
 - Recommendations and degree of participation in medical decision-making
 - quality versus length of life
 - Location of palliative care or place of death vary between individuals
 - May evolve over time
 - Clinicians should be cautious about generalizing palliative care needs from one patient to another

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Diversity of Experience

- The rank importance of common symptoms and care needs also differs between patients and their caregivers [
- **Rankings** of the most important goals and most burdensome symptoms change over time.
- This finding underscores the importance of both planned reassessments (of symptoms and goals) and eliciting patient's own ranking
- The presence of a symptom as seemingly universally undesirable as pain is subject to individual interpretation and varying treatment preferences.
- A 2010 review of guidelines and policies from the United States, United Kingdom, Canada, and Australia found few uniform sets of fixed patient expectations and clinical standards for palliative care.

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Diversity of Experience

- **Interpersonal sources of suffering** — In addition to individual sources of suffering, palliative care patients face anticipatory grief, which often leads them to relate to their families, other loved ones, communities, and professional caregivers with strong emotions.
 - While these relationships are commonly supportive and adaptive, the distress felt by each of these parties (i.e., patient, family or other loved ones, and clinician) may negatively impact the others. As examples:
- **In the case of impending disease progression despite treatment, a patient's hope and trust in their clinician may, due to countertransference, be inadvertently associated with the emergence of grief and self-doubt on the part of the clinician**
 - These emotions, in turn, may affect therapeutic decisions and wellbeing of the patient, family, and the clinicians themselves as well as very close and ongoing introspection on the part of the clinician

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Diversity of Experience

- Oncologists may alter treatment decisions, experience an overwhelming sense of responsibility , and distance themselves or withdraw from both the patients and their families or loved ones as the patient gets closer to death
- In another study, a stronger doctor-patient relationship was associated with lower prognostic accuracy on the part of the physician
 - A fact which could potentially alter a treatment plan

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Diversity of Experience

- In a study of Medicare patients, individual physician characteristics (rather than the patients' medical comorbidity, age, race, or sex) had the strongest predictive value of the type of end-of-life care (e.g., hospice versus intensive care unit [ICU] care) received by patients
- These findings illustrate the need for comprehensive evaluation of not only the patient but also their family or other loved ones, caregivers, and environment, as well as very close and ongoing introspection on the part of the clinician

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Gaps in Assessment

- Traditional methods of clinical assessment (i.e., the interview, physical examination, and diagnostic workup) and care planning frequently miss many target symptoms for palliative care management, particularly in diseases other than cancer
- Patients who have an advanced and/or life-threatening illness are frequently reluctant to discuss specific issues related to prognosis or advance care planning while
- Clinicians who lack a comprehensive, structured assessment approach risk underdiagnosing suffering and failing to discern actual patient needs or preferences

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Gaps in Assessment

The discordance between patient-reported and clinician-documented symptoms was shown in a study that with advanced cancer and their paired physician-completed medical records

- There was good concordance for pain (96 percent).
- But patients reported most other symptoms or problems more often than did their doctors
- The discordance, in turn, is associated with patient distress and poor quality of life

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Gaps in Assessment

- These findings suggest that individual sources of suffering, preferences, and palliative care plans for specific patients can be formulated only through comprehensive and uniquely structured palliative assessment
- Differs from traditional medical evaluation.
- Some data suggest that such a comprehensive approach improves the documentation of patient needs
- Whether patient outcomes are improved remains unclear

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Unique Aspects of Palliative Assessment

- While there is a consensus on the domains of assessment, structure and process of care, and quality metrics for palliative care and clinical programs, a standard format of clinical palliative care assessment has not been established
- In general, while including the traditional components of medical evaluation (medical and psychosocial history, physical examination), comprehensive palliative assessment involves unique content, focus, and sources of information:

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Content

• Comprehensive palliative assessment includes six unique domains examined in a structured manner:

- 1) Pain and other physical symptoms
- 2) Psychological, psychiatric, cognitive symptoms, and resources (coping)
- 3) Illness understanding and care preferences (i.e., personal goals, expectations, understanding of illness trajectory and risks versus benefits of therapies)

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Content

- 4) Social and economic resources and needs of patients and caregivers, including for care in the home
- 5) Existential and spiritual concerns
- 6) Continuity of and coordination of care across settings

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Focus

- The unit of care in palliative care consists of both the patient and their family or other loved ones
- Accordingly, comprehensive palliative assessment is patient-focused and family-oriented
- The patient's own frequently competing and evolving care preferences and goals, rather than solely pathophysiologic and clinical data, define the focus and organization of the assessment.

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Treatment Planning

- Rather than gathering information exclusively from the patient (or caregivers) and medical records, palliative evaluation utilizes a broad range of sources, each contributing to the final assessment
- Interdisciplinary manner- the clinician collaborates with nursing staff, chaplains, social workers, therapists, and nutritionists to perform discipline-specific evaluative tasks, together developing the comprehensive palliative assessment

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Treatment Planning

- Tasks that are best shared with expert non-clinician team members may include evaluation of existential and spiritual domains, economic needs, and care coordination
- Specific distribution will vary depending on local expertise.

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Assessment

- The palliative assessment must be grounded in an attitude of openness towards the other person and being present to the other's suffering
- When this occurs, the diagnostic evaluation itself may become a part of the therapeutic intervention
- This concept is embodied in the words of the Boston physician, Alfred Worcester, remarking on the care of the aged and the dying, who said, "In the practice of our art it often matters little what medicine is given, but matters much that we give ourselves with our pills"

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Assessment

- 1. Good communication skills are necessary. While assessing symptoms and burdens in a focused manner
- 2. Open-ended questions and actively listening to the answers after questions are asked
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Assessment

- Aided by using:
 - Empathic comments
 - Reframing
 - Speaking in the patient's own language and level of understanding
 - Exploring both the cognitive and emotional meanings of the response
 - Acknowledging and legitimizing the individual's values and concerns communicates respect
 - Leads to an enhanced sense of dignity
 - May reduce rates of anxiety and depression in patients and their relatives

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Identifying Criteria

- **A potentially life-limiting or life-threatening condition and...**
- **Primary criteria^a**
 - The "surprise question^b": You would not be surprised if the patient died within 12 months or before adulthood
 - Frequent admissions (e.g., more than one admission for same condition within several months)
 - Admission prompted by difficult-to-control physical or psychological symptoms (e.g., moderate to severe symptom intensity for more than 24 to 48 hours)
 - Complex care requirements (e.g., functional dependency; complex home support for ventilator/antibiotics/feedings)
 - Decline in function, feeding intolerance, or unintended decline in weight (e.g., failure to thrive)
- **Secondary criteria^a**
 - Admission from long-term care facility or medical foster home^d
 - Older patient, cognitively impaired, with acute hip fracture
 - Metastatic or locally advanced incurable cancer
 - Chronic home oxygen use^e
 - Out-of-hospital cardiac arrest
 - Current or past hospice program enrollee^d
 - Limited social support (e.g., family stress, chronic mental illness)^d
 - No history of completing an advance care planning discussion/document

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Components

- **Pain/symptom assessment**
 - Are there distressing physical or psychological symptoms?
- **Social/spiritual assessment**
 - Are there significant social or spiritual concerns affecting daily life?
- **Understanding of illness/prognosis and treatment options**
 - Does the patient/family/surrogate understand the current illness, prognostic trajectory, and treatment options?
- **Identification of patient-centered goals of care**
 - What are the goals for care, as identified by the patient/family/surrogate?
 - Are treatment options matched to informed patient-centered goals?
 - Has the patient participated in an advance care planning process?
 - Has the patient completed an advance care planning document?
- **Transition of care post-discharge**
 - What are the key considerations for a safe and sustainable transition from one setting to another?

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Domains of Assessment

- A comprehensive palliative assessment is rarely completed in one session
- Frequently extends over multiple encounters
 - Complexity of clinical content
 - Time required to develop necessary quality of life and reduced depressive symptoms
 - A patient's personality and cultural can determine whether the emotion regulation style is adaptive or maladaptive.

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Physical Symptoms

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Domains

- Physical Symptoms
- Psychological, psychiatric and Cognitive
- Depression
- Anxiety
- Maladaptive copings
 - Psychological issues specific to caregivers
- Illness understanding and care preferences
- Ramifications and accurate illness understanding
- Social and economic needs of patients and their caregivers
- Religious, spiritual and existential issues
- Care coordination and continuity

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