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IN PALLIATIVE CARE

Interprofessional Webinar Series

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Care of the Imminently Dying

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Care of the Imminently Dying

- How do patients with advanced illness die?
- Predicting a short survival
- Palliative care at the end of life

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Care of the Imminently Dying

- How do patients with life-limiting illnesses die?
  - An acute complication brings on rapid decline to active dying
  - Progressive chronic illness brings on steady decline into active dying

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Care of the Imminently Dying

- How do patients with life-limiting illnesses die?
  - An acute complication brings on rapid decline to active dying
  - Progressive chronic illness brings on steady decline into active dying

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Care of the Imminently Dying

- Some complications are an expected part of the disease
  - Exacerbation of heart failure
  - Exacerbation of COPD
  - Decline after stopping dialysis

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Care of the Imminently Dying

- Other acute complications are not expected
  - Sepsis
  - Hemorrhage
  - Pulmonary embolism
  - Stroke

Acute Complication: Clinical Imperatives

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- Understand the medical context
  - Diagnosis and pathophysiology
  - Available treatments for the complication
    - Likely benefits, and risks/burdens
- Be prepared (especially if unexpected) for
  - “Why” questions
  - Desire to revisit goals and decisions
  - Potential for guilt

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Acute Complication: Clinical Imperatives

- Be prepared to change a key message
  - "*Could be weeks or months…*" ⟶ *"Could be hours or days…"*

Acute Complication: Clinical Imperatives

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- When an acute complication occurs
  - **Evaluate and understand** the medical facts and decisions
  - **Review and coordinate care** with all treatment teams
  - **Assess patient** for physical, emotional, psychological, spiritual, and concrete needs
  - **Assess family caregivers** for emotional, psychological, spiritual, and concrete needs
  - **Review and modify** the palliative plan of care
  - **Communicate** with the family to explain, establish new goals and expectations, and provide support

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Care of the Imminently Dying

- How do patients with life-limiting illnesses die?
  - An acute complication brings on rapid decline to active dying
  - Progressive chronic illness brings on steady decline into active dying

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Care of the Imminently Dying

- Decline into a phase of active dying
  - Can occur over weeks or longer
  - Often not appreciated by physicians, who usually overestimate prognosis
- Offers a longer period to modify and optimize the palliative plan of care

Identifying Patients Likely To Die "Very Soon"

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- Although all indicators of short survival are subject to error, available information is actionable
- Performance status is a useful indicator
  - Performance status scales
    - Karnofsky Performance Status scale
    - Palliative Performance Scale
    - ECOG scale

Identifying Patients Likely To Die "Very Soon"

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- Palliative Performance Scale
  - Study of 466 hospice patients
    - **PPS of 30-40**
      - **58% died within 1 month and 80% died within 3 months**
    - **PPS of 50-70**
      - **33% died within 1 month and 69% died within 3 months**
    - Overall, somewhat more predictive for noncancer vs. cancer diagnoses, and for NH vs. non-NH residence

(Harrold et al, 2005)

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Palliative Performance Scale

%	Ambulation	Activity and Evidence of Disease	Self-care	Intake	Conscious Level
70	Reduced	Unable Normal Job / Work Some Evidence of Disease	Full	Normal or Reduced	Full
60	Reduced	Unable Hobby / House Work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance Necessary	Normal or Reduced	Full or Confusion
40	Mainly in Bed	As Above	Mainly Assistance	Normal or Reduced	Full or Drowsy or Confusion
30	Totally Bed Bound	As Above	Total Care	Reduced	Full or Drowsy or Confusion

Identifying Patients Likely To Die "Very Soon"

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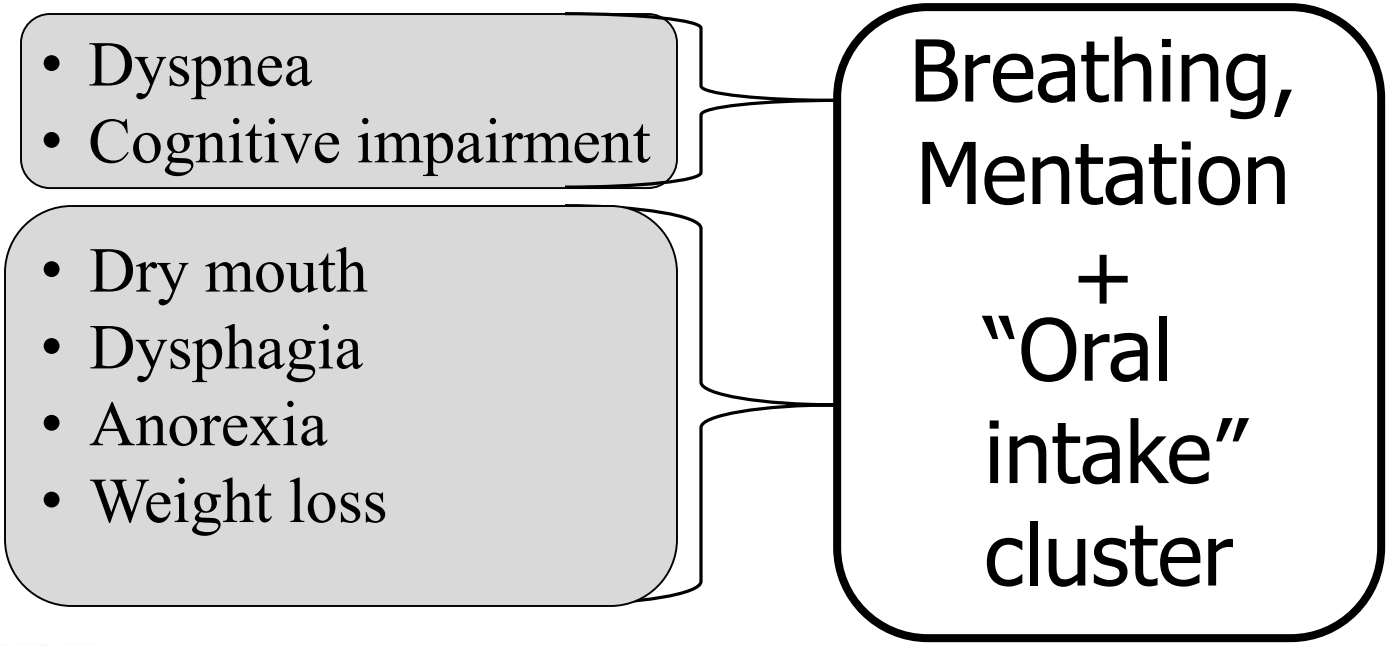
- Cancer studies suggest that symptoms and signs can improve estimation of prognosis



Vigano et al, 2000

Identifying Patients Likely To Die "Very Soon"

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- Tools have been developed to further enhance prediction of survival
  - **Palliative Prognostic Score (PaP)**
    - Clinical Prediction of Survival (CPS)
    - Karnofsky Performance Status
    - Anorexia
    - Dyspnea
    - WBC count
    - Lymphocyte percentage

Identifying Patients Likely To Die "Very Soon"

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- Tools have been developed to further enhance prediction of survival
  - **Palliative Prognostic Index (PPI)**
    - Palliative Performance Scale
    - Oral intake
    - Edema
    - Dyspnea at rest
    - Cognitive impairment

Identifying Patients Likely To Die "Very Soon"

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- Bedside perspective:
  What should experienced clinicians assess?
  - **First, declining performance status**
    - More time in bed or chair
    - More help needed in ADLs
    - More time drowsy or asleep

Identifying Patients Likely To Die "Very Soon"

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- Bedside perspective:
  What should experienced clinicians assess?
  - **Second, specific symptoms/signs**
    - "Breathing, mentation, and oral intake cluster"

Declining Prognosis: Clinical Imperatives

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- When patients have symptoms/signs suggesting that death is probably soon—days to weeks
  - **Evaluate and understand** the medical facts and decisions
  - **Review and coordinate care** with all treatment teams
  - **Assess patient** for physical, emotional, psychological, spiritual and concrete needs
  - **Assess family caregivers** for emotional, psychological, spiritual and concrete needs
  - **Review and modify** the palliative plan of care
  - **Communicate** with the patient/family to explain, establish new goals and expectations, and provide support

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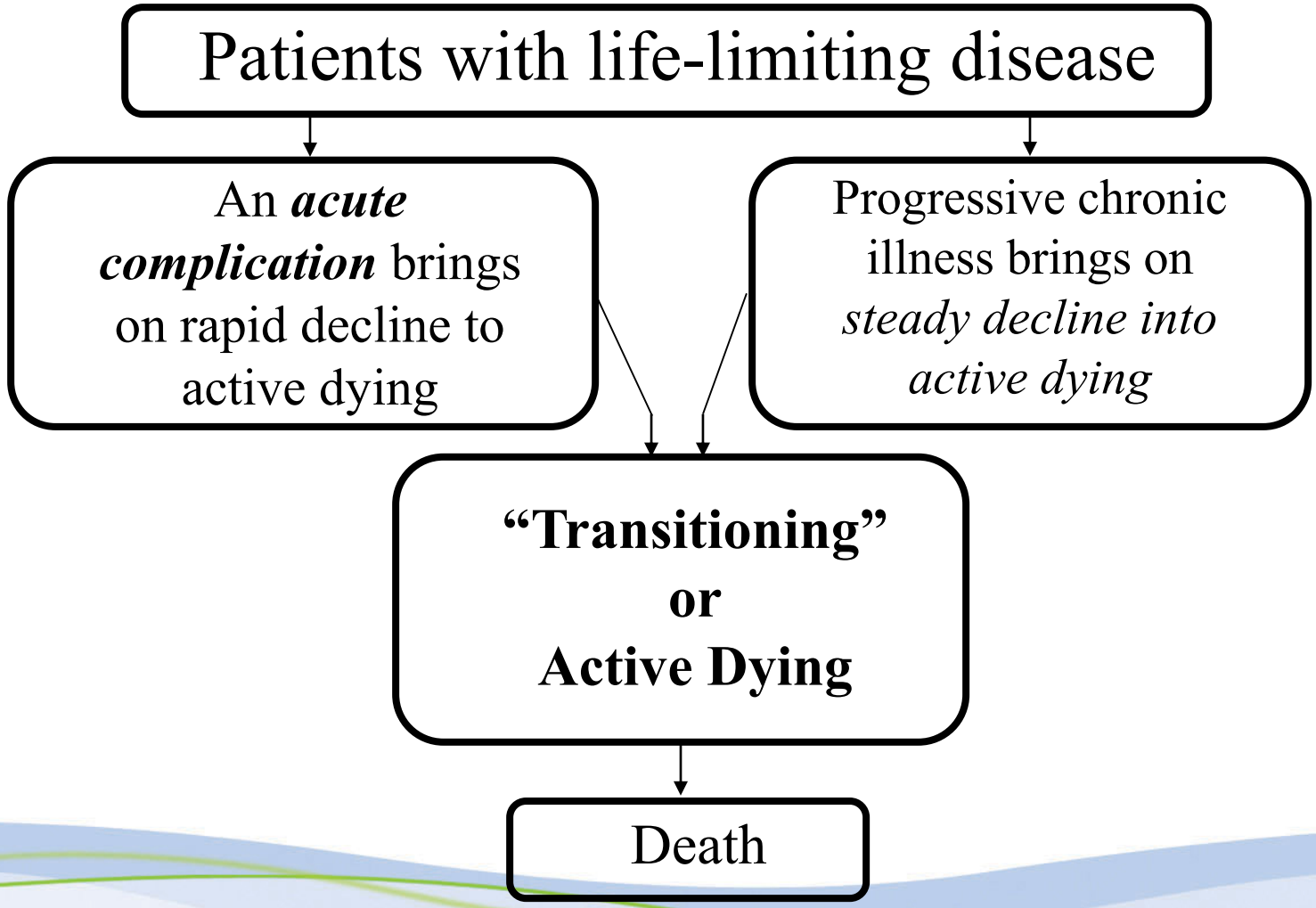
Identifying the Actively Dying



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Identifying the Actively Dying

- Prospective study of inpatients with cancer (N=357) to identify signs associated with death in ≤3 days
  - Of 52 signs evaluated, 8 were highly specific
    - Nonreactive pupils
    - Decreased response to verbal stimuli
    - Decreased response to visual stimuli
    - Inability to close eyelids
    - Drooping of the nasolabial fold
    - Hyperextension of the neck
    - Grunting of vocal cords
    - Upper gastrointestinal bleeding

Hui D, Cancer 2015;121:960-7

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Identifying the Actively Dying

- Clinical observations highlight other predictors
  - Changes in responsiveness
    - Declining response to voice and contact
    - Sometimes sleep-like, sometimes eyes open ('vigilant'), and sometimes episodes of agitation

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Identifying the Actively Dying

- Clinical observations highlight other predictors
  - Changes in muscle activity
    - Decreased muscle tone
    - Myoclonic jerks
  - Changes in urinary function
    - Incontinence
    - Declining output

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Identifying the Actively Dying

- Clinical observations highlight other predictors
  - Changes in breathing
    - May be shallow and rapid
    - Sometimes slowed
    - Cheyne-Stokes respiration, with apneic periods
    - Noisy, progressing to “death rattle”

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Identifying the Actively Dying

- Clinical observations highlight other predictors
  - Changes in skin
    - Extremities become cool, mottled or cyanotic
    - Sometimes increased sweating
    - Skin of the face and body may be abnormal
      - Mildly cyanotic, flushed, pale or “yellowish”

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Identifying the Actively Dying

- Clinical observations highlight other predictors
  - Changes in vital signs (if taken)
    - Blood pressure usually low
    - Pulse usually increased
    - Temperature increased or decreased
    - Respirations increased or decreased

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When Death Is Soon: Clinical Imperatives

- Management of the imminently dying patient is a ***best practice in specialist palliative care***
  - One of the eight domains identified by the National Consensus Project for Best Practices in Palliative Care

(http://www.nationalconsensusproject.org/guideline.pdf)

When Death Is Soon: Clinical Imperatives

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- Effective management requires specialist competencies in
  - Communication
  - Multidimensional assessment
  - Management of diverse sources of distress for the patient and family: Physical, psychiatric and psychosocial, and spiritual/existential or religious
- All competencies informed by cultural sensitivity, working knowledge of clinical bioethics, and understanding of system-level resources and mandates

When Death Is Soon: Clinical Imperatives

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- Foundations for effective communication
  - Be informed about the medical facts of the case
  - Be aware of language, culture and extent of acculturation
  - Be aware of education and health literacy
  - Be aware of psychiatric and psychosocial barriers

When Death Is Soon: Clinical Imperatives

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- In-the-moment effective communication
  - Be aware of nonverbal communication
  - Plan on multiple short conversations
  - Demonstrate willingness to have difficult discussions
  - Be honest, but avoid categorical or definitive statements when there is reasonable uncertainty
  - Express feelings but maintain appropriate professional boundaries
  - Normalize concerns
  - Engage in empathic listening

When Death Is Soon: Clinical Imperatives

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- Elements of empathic listening
  - Includes emotional identification, compassion, expression of feelings, and insight
  - Listen more than speak
    - Ask questions to learn what the patient or family knows and what is uncertain
    - Ask questions to explore emotional reaction and methods for coping with knowledge and uncertainty
  - Repeat back to ensure understanding

When Death Is Soon: Clinical Imperatives

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- Key assessment issues
  - Reassess decision making if a change has occurred in the patient's decisional capacity or in the identified decision maker

When Death Is Soon: Clinical Imperatives

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- Considerations when decisional capacity is lost
  - Are there oral or written advance directives?
  - Is there an agent (selected by the patient)?
    - If so, is the agent available, informed, able to act with substituted judgment or with best interests
  - Is there a surrogate (selected by someone else)?
    - If so, is the surrogate legal, available, informed, able to act with substituted judgment or with best interests
  - What is the relationship between the agent/surrogate and other family members?

When Death Is Soon: Clinical Imperatives

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- Key assessment issues
  - Reassess goals of care
    - Are medical treatments needed?
    - Should medical treatments be withdrawn?

Withdrawing Medical Treatments in Advanced Illness

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- Consider benefits and burdens of stopping existing medical therapies
- For treatments not considered ‘life-sustaining’, lack of evidence is the challenge
- New study strongly supports discontinuation of statins
  - Randomized, multicenter trial in 381 patients
  - No significant difference in mortality
  - QOL better for the discontinuation group (P = .04)
  - Mean cost savings for the discontinuation group was $716 per patient

Kutner JS, et al, JAMA Int Med 2015

Withdrawing Medical Treatments in Advanced Illness

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- For therapies considered life-sustaining
  - Discontinuation for a medical contraindication should be no different from any other therapy
  - Discontinuation because of perceived futility requires a benefit-to-burden analysis with medical and legal/ethical considerations
    - Who requests and who consents if the patient lacks capacity?
    - What is futility and burden for the individual?
    - What are the cultural and religious issues?

When Death Is Soon: Clinical Imperatives

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- Key assessment issues
  - Should the patient stay at home?
    - Is there a need for more aggressive symptom control that would be difficult to accomplish at home?
    - Are there appropriate disease-modifying treatments that must be given in the hospital?
    - What are the patient's expressed wishes about hospitalization?
    - Can the family cope?

When Death Is Soon: Clinical Imperatives

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- Treat symptoms/disorders associated with patient/family distress
  - Symptoms must be addressed if the patient is able to experience them
    - Pain, breathlessness, anxiety, others
  - Other problems should be treated
    - Noisy respirations
    - Oral lesions or dryness
    - Wounds and ulcers
    - Delirium

When Death Is Soon: Clinical Imperatives

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- Terminal delirium
  - Acute disorder of consciousness, attention, and cognition
  - Can be hyperactive, hypoactive, or mixed
  - Distinguish hypoactive delirium from somnolence/coma
  - Symptoms of delirium
    - Restlessness
    - Anxiety
    - Sleep disturbance: Insomnia, drowsiness, sleep reversal
    - Tremulousness
    - Fluctuating concentration or attention
    - Illusions/hallucinations

When Death Is Soon: Clinical Imperatives

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- Management of terminal delirium
  - Consider reversible causes, e.g., hydration
  - Environmental interventions, e.g. position near window, remove objects from the room, person at the bedside
  - Neuroleptic therapy, e.g., haloperidol
  - Sedative/hypnotic for agitation, e.g., lorazepam

When Death Is Soon: Clinical Imperatives

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- Palliative sedation in the management of refractory symptoms near the end of life
  - *A medical treatment by which a patient who is believed to be near the end of life is given a drug with the goal of producing sedation sufficient to relieve suffering*
    - Widely accepted when physical symptoms are refractory to conventional therapy near the end of life
    - Ethical practice predicated on *proportionality* of treatment and *principle of double effect*
    - Can be done at home

Gurschick L, et al; Am J Hosp Palliat Care 2014

When Death Is Soon: Clinical Imperatives

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- Conclusions
  - Care of the imminently dying is a 'best practice' in specialist palliative care—for all disciplines
    - Requires skills in recognizing and reacting to "dying soon" and "active dying"
    - Requires broad clinical competencies in communication, assessment, management of diverse sources of patient and family distress
    - Requires professionalism, confidence, and a supportive team

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Care of the Imminently Dying

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