

End-of-Life Care

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Adapted from the Education in Palliative and
End-of-life Care for Oncology (EPEC-O) Curriculum

Preparing for the End of Life

- Timeline of end stages unpredictable
- Privacy and intimacy important
- Anticipate need for medications, equipment, and supplies
- Prevent surprises
- Regularly review the plan of care with the patient, family, and caregivers

Physiologic Changes During the Dying Process

- Increasing weakness and fatigue
- Decreasing appetite and fluid intake
- Decreasing blood perfusion
- Neurologic dysfunction
- Pain
- Loss of ability to close eyes

Weakness and Fatigue

- Decreased ability to move
- Joint-position fatigue
- Increased risk of pressure ulcers
- Increased need for care
 - Activities of daily living
 - Turning, movement, and massage

Decreased Appetite and Food Intake

- Family fears: “giving in” and/or starvation
- Reminders
 - Food may be nauseating
 - Anorexia may be protective
 - Risk of aspiration
 - Clenched teeth express desires, control
- Help family find alternate ways to express care and love for the patient

Decreased Fluid Intake

- Oral rehydrating fluids
- Family fears: dehydration and/or thirst
- Reminders
 - Dehydration does not cause distress
 - Dehydration may be protective
- Parenteral fluids may be harmful
 - Fluid overload, breathlessness, cough, and secretions
- Mucosa and conjunctiva care

Decreased Blood Perfusion

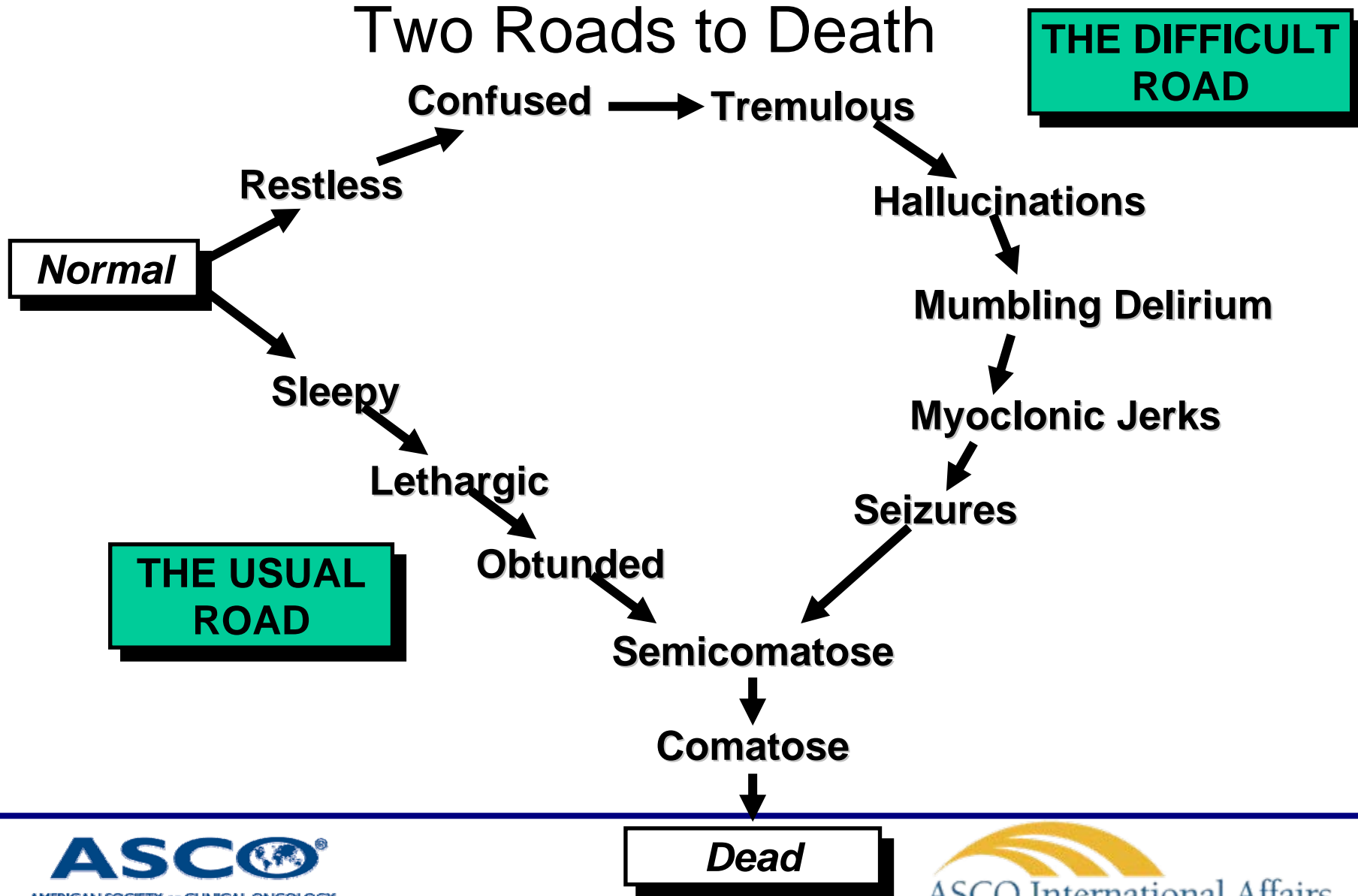
- Tachycardia, hypotension
- Peripheral cooling, cyanosis
- Mottling of skin
- Diminished urine output
- Parenteral fluids will not reverse

Neurologic Dysfunction

- Decreased level of consciousness
- Communication with the unconscious patient
- Terminal delirium
- Changes in respiration
- Loss of ability to swallow and to control sphincter

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Two Roads to Death



Decreasing Level of Consciousness

- “The usual road to death”
- Progression
- Eyelash reflex

Terminal Delirium

- The “difficult road to death”
- Family needs support, education
- Seizures

Medical management

- Benzodiazepines
 - Lorazepam, midazolam
- Neuroleptics
 - Haloperidol, chlorpromazine

Changes in Respiration

- Altered breathing patterns
 - Diminished tidal volume, apnea, Cheyne-Stokes respirations, accessory muscle use, last reflex breaths
- Fears
 - Suffocation
- Management
 - Family support
 - Oxygen may prolong dying process
 - Low doses of opioids or benzodiazepines for breathlessness

Loss of Ability to Swallow

- Loss of gag reflex
- Accumulation of saliva, secretions
 - Scopolamine to dry secretions
 - Postural drainage
 - Positioning
 - Suctioning

Loss of Sphincter Control

- Incontinence of urine, stool
- Family needs knowledge, support
- Cleaning, skin care
- Urinary catheters
- Absorbent pads, surfaces

Pain in the Last Hours of Life

- Myth of increased pain with dying
- Assessment of the unconscious patient
 - Sustained grimace, behaviors
 - Persistent versus fleeting grimaces
 - Incident versus rest pain
 - Distinction from terminal delirium
- Management when there is no urine output
 - Stop routine dosing, infusions of morphine
 - Breakthrough dosing as needed
 - Least invasive route of administration

Loss of Ability to Close Eyes

- Loss of retro-orbital fat pad
- Insufficient eyelid length
- Conjunctival exposure
 - Increased risk of dryness, pain
 - Maintain moisture

Medications

- Limit to essential medications
- Choose less invasive route of administration
 - Buccal mucosal or oral first, then consider rectal
 - Subcutaneous, intravenous rarely
 - Intramuscular almost never

Dying in Institutions

- Home-like environment
 - Permit privacy, intimacy
 - Allow for personal items, photos
- Continuity of care plans
- Avoid abrupt changes of settings
- Consider a specialized unit

Which type of Institution?

- Cancer Centre
- General Hospital
- Low-intensity Hospital
- Hospice
- Home

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HOSPICE

Great Britain 1967: Dame Cicely Saunders founds St. Christopher Hospice.

Philosophy of Hospice:

- Open admission and stay
- Family environment
- Continuous care
- Multidisciplinary approach to all symptoms with special emphasis to pain

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Definition of palliative care according to the European Association of Palliative Care (EAPC)

“Palliative care is total care provided to persons with disease no more amenable to treatments aimed at recovery.

The control of pain, of other symptoms and of psychologic, social and spiritual issues is of primary importance.”

HOSPICE VIA DI NATALE AVIANO - PORDENONE

- Opened in 1996
- Privately planned and financed
- Hospice similar to a family house, in a countryside surrounding
- 3-storey building:
 - Ground floor and first floor: 34 miniflats for patients and family members under treatment in the nearby Cancer Institute
 - Second floor: Hospice



Questa casa è il frutto
della generosità della gente
del nostro Paese.

via di Natale





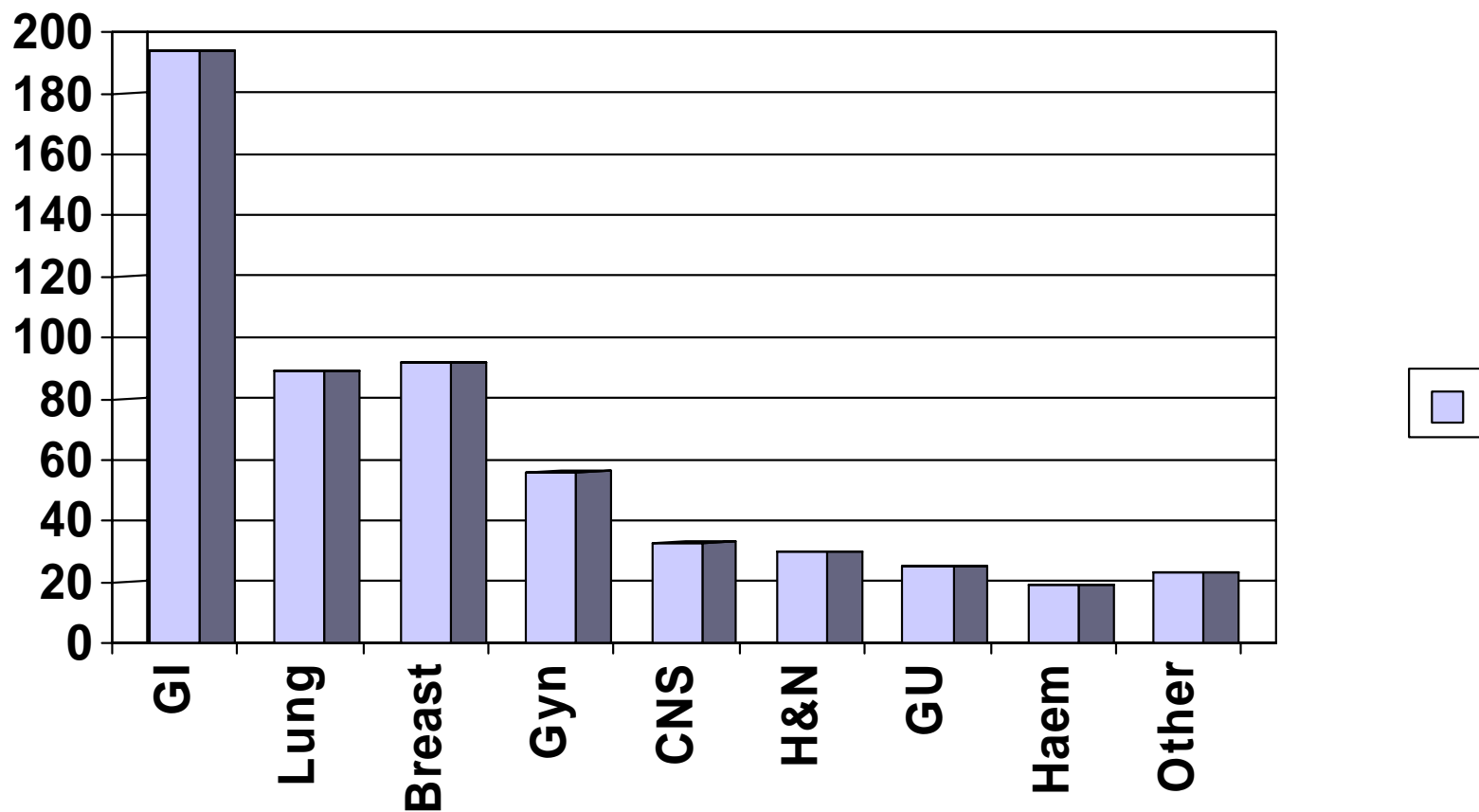




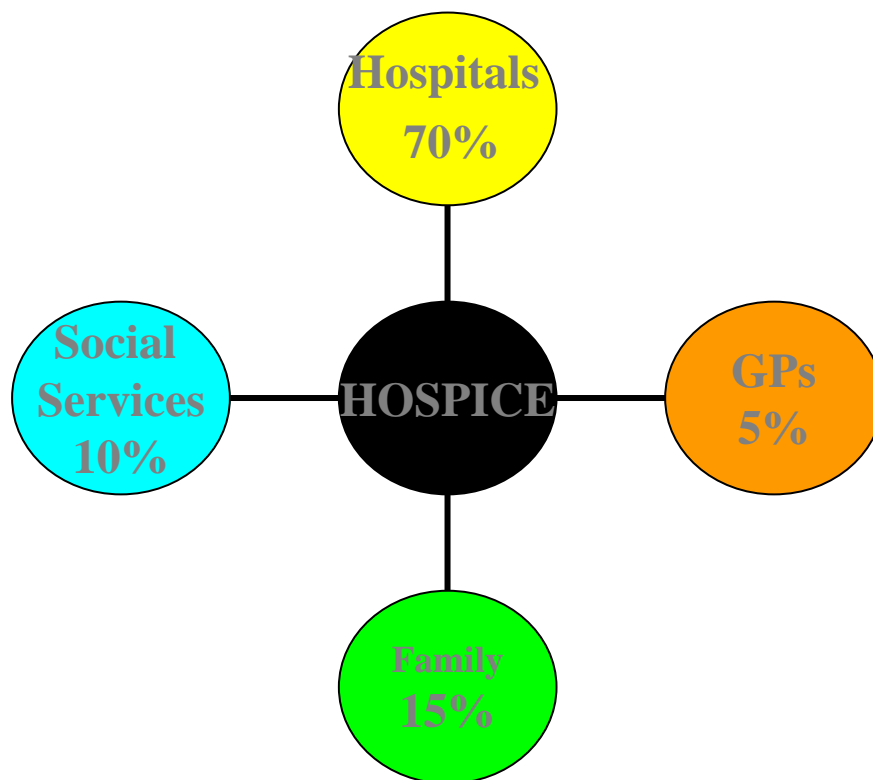


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NUMBER OF PATIENTS
1999 – 2004



PATIENT REFERRAL



As Expected Death Approaches

- Discuss
 - Status of patient, realistic care goals
 - Role of physician, interdisciplinary team
- Reinforce signs, events of dying process
 - Translate what onlookers see into what patient is experiencing
 - Personal, cultural, religious, rituals, funeral planning
 - Family support throughout the process

Immediate Time of Death

- Verify absence of heartbeat, respirations
- Confirm details of death
- Explain pronouncement process to family members
- Perform pronouncement
- Document for medical record

Bereavement Care

- Attendance at funeral
- Condolence notes

Summary

- End-of-life care is as important as any other time in cancer care
- Management principles are the same for at home or in a health care institution
- Family members and other caregivers should be informed about what to do and what to expect
- Care for the family does not end with the patient's death