***Care of Dying Patient***

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**Euthanasia** – see p. 4667

**Examination** of terminal patient – see p. Exam1

**Suffering** - global perception of distress due to factors that, together, undermine quality of life (e.g. pain; physical impairment; psychologic disturbances; social, family, financial, and spiritual concerns).

Dying Patient

People differ in what they consider important when facing death:

* *some people* ***search for closure***: reach out to friends and family to share time and to express love; they complete projects important to their lives; and they tie up loose ends; with appropriate support, people die at time and in way that allows them to experience satisfying close.
* *other people* ***cannot accept their imminent mortality*** and avoid such closure; struggle for life to be prolonged, even at cost of pain, marked confusion, or severe respiratory distress.
* for others, ***quality of life*** is overarching concern - they prefer comfort measures rather than prolonged disability and struggle.

Patients who fear pain or confusion more than death should be treated differently from those who cherish every moment of life, regardless of its quality.

* many patients ask *whether time until death can be predicted*;
* often, such estimates are incorrect (esp. for disorders in which death tends to come suddenly, without reliable warning signs - heart failure, emphysema).
* for other disorders (e.g. commonly cancer), recognizable changes may presage death by several weeks or months.

N.B. many people live for months or years in very fragile state of health!

* **supportive care** may be only realistic goal for dying patient.
* patients should be told that their disorder is likely to cause death (even when time frame is unclear); when death becomes imminent, they should be told.

Health care practitioner must not assume that patients / family members understand fatal nature of certain disorders (even metastatic cancer) or that they recognize when patient is nearing death!

* do not delay full disclosure too long - doing so can give patients and family members false hope and reduce opportunity for attending to spiritual and family concerns.
* explain how disorder will worsen, how death will come, and assure that physical symptoms will be controlled.
* *effective care involves team* because no one caregiver is available 24 h/day and because skills and perspectives of several disciplines are needed.
* best - **palliative care** or **hospice teams**.
* when death is imminent, experienced team member can comfort family members and may prevent inappropriate call to emergency medical system.
* at some point, virtually every dying patient should have do-not-resuscitate (DNR) order written in medical record - all clinicians in every setting should abide by that decision!

Emotional reactions of patients

Stages by Elisabeth Kübler-Ross (Swiss psychiatrist):

N.B. not all stages are readily observable in every individual

* + - * clinician’s goal is to determine what stage person is experiencing.
			* it is inappropriate to “help patient move along” from one stage to another – individuals progress at their own pace and order (some not “finishing” all stages before death)
1. **Denial (isolation)** – patients refuse to believe what is happening;
	* patient believes there is mistake (and finds many examples of such mistakes).
	* patient may be reluctant to discuss illness.
	* patients feel removed, isolated, separated from other people (an even “whole world”).
2. **Anger** – patients ask “Why me?”
	* resentment and blame are directed at family members, caregivers, or even God.
	* patients may envy others who they feel “deserve” this more than they do.
	* anger may be strong!!! (up to extreme hostility)
3. **Bargaining** – patients practice good behavior in exchange for postponement of inevitable.
	* goals are set, “if …, then …” situations are constructed.
	* even God may be approached as agent for bargaining.
	* prior guilt-provoking incidents are examined, and opportunities for forgiveness may be requested.
4. **Depression**

**Reactive depression** – patients respond to losses (e.g. losses of bodily functions and abilities.

**Preparatory depression** (“anticipatory stage”) – preparatory grief experienced prior to final departure from this world.

1. **Acceptance** –peacefulness, rest, limited verbal and physical interactions; patients withdraw, and their circle of interest diminishes dramatically.
	* it is difficult time for family members, because behavior looks like “giving up”
	* reassurances by and physical presence of family members / caregivers are critical during this time!

Concerns of patients

- patients typically concern:

* 1. ability to tolerate pain
	2. loss of personal dignity
	3. being abandoned (physically / psychologically)
	4. becoming burden
	5. perceived reluctance of family members / caregivers to be honest
	6. exclusion from decision-making process

Hospice Care

**Hospice** is concept as well as program of care; may be provided:

1. at home
2. in nursing home
3. in another care facility (hospitals and rehabilitation centers do not provide such care!)
* specifically designed to minimize suffering for dying patients and their family members.
* it forgoes most diagnostic testing and life-prolonging treatments in favor of symptom relief, education of patients and family members about appropriate care, and comfort care.
* always interdisciplinary - physicians, nurses, and attendants (e.g. home health aides), pharmacists, nutritionists, therapists.
* can provide most necessary medical treatments.
* Medicare or insurance pays for most home hospice services, but usually ***only after physician certifies*** that patient has terminal disorder and that life expectancy (in usual course) is < 6 mo (physicians are often reluctant to certify such 6-mo prognosis - in US, hospice care tends to be started very late in fatal disorders).

Family

* physician should prepare family members for death far in advance.
* if patient is expected to die at home:
	+ tell family members ***whom to call*** (e.g. physician, hospice nurse) and ***whom not to call*** (e.g. ambulance service).
	+ often, specific actions are required at home (e.g. to have needed ***drugs***).
	+ tell family members how to obtain ***legal advice*** and to ***arrange burial*** or ***cremation*** services.
* tell about ***changes that may occur in patient's body*** directly before and after death (irregular breathing, cool extremities, confusion, purplish skin color, somnolence).

Symptom Control

Physical and mental distress is common!

* comfort measures, including nonspecific treatment or short sequential trial of empiric treatments, are often better than exhaustive diagnostic evaluation.
* symptom can have many causes and may respond differently to treatment as patient's condition deteriorates - treatments must be closely monitored and repeatedly reevaluated.
* avoid drug overdosage / underdosage!
* sometimes *fear that symptom will worsen* can be more crippling than symptom itself, and reassurance that effective treatment is available may be all patient needs.

Pain

- see S20 p.

* there is no evidence to suggest that any pains can suddenly increase as patient dies.
* ***continuous pain*** in semiconscious or obtunded patient may be associated with grimacing and continuous facial tension, particularly across forehead and between eyebrows; do not confuse with terminal delirium (if diagnosis is unclear, trial of higher dose of opioid\* may be necessary to judge whether pain is driving observed behaviors).

\*but if patient has had good pain control with regular doses of morphine, opioids↑ can provoke delirium

Dyspnea

- one of most feared symptoms; may be treatable (e.g. antibiotics for pneumonia, thoracentesis for pleural effusion). about death rattles – *see below*

* patients can be made comfortable without invasive or aggressive measures, regardless of cause of dyspnea:
1. **O2 by nasal cannula** (at least, psychologically comforting).
2. drugs to dry airway secretions (e.g. topical scopolamine gel 0.25-0.5 mg q8-12h, hyoscyamine 0.125 mg sublingually q8h, diphenhydramine 10-50 mg IM q4-6h prn).
3. **nebulized saline** - to treat viscous secretions.
4. nebulized albuterol and oral / injectable **corticosteroids** – for bronchospasm and bronchial inflammation.
5. nondrug measures - cool draft from open window or fan, maintaining calming presence.
* for terminal dyspnea:
1. morphine 2-10 mg\* sublingually or 2-4 mg sc q2-4h prn helps reduce breathlessness (*blunted medullary response* to CO2 retention or O2 decline).

\*doses for respiratory symptoms are much higher than for pain.

1. **benzodiazepines** relieve anxiety associated with dyspnea.

Anorexia

* most dying patients lose their appetite. [also see p. 2768 >>](file:///D%3A%5CViktoro%5CNeuroscience%5CUSMLE%202%5CEndocrine%20system%2C%20metabolism%20%282701-2800%29%5C2768.%20Nutritional%20Support.doc#Terminal_stages)
* offer favorite foods.
* gastritis, constipation, oral candidiasis, pain, nausea - should be treated.
* **appetite stimulants** - oral corticosteroids (dexamethasone 2-8 mg bid or prednisone 10-30 mg once/day) or megestrol 160-480 mg/day po.
* ***oral hygiene*** (brushing teeth, swabbing oral cavity, applying lip salve, and providing ice chips for xerostomia) is valuable part of care.
* once patient is unable to swallow, cease oral intake.
* if patient is close to death, family members should be counseled that neither food nor hydration is necessary to maintain patient's comfort (IV fluids, TPN, tube feedings do not prolong life and may increase discomfort and may hasten death, e.g. due to aspirations, pulmonary edema); **dehydration** causes ***endorphin*** ***release*** and **caloric restriction** causes ***ketosis*** → analgesic effects and absence of discomfort.
	+ only discomfort due to dehydration near death is xerostomia; H: oral swabs or ice chips, moisten and clean oral mucosa q 15-30 mins with either baking soda mouthwash (1 teaspoon salt, 1 teaspoon baking soda, 1 quart tepid water) or artificial saliva.

N.B. rehydration alone may not resolve xerostomia.

* + family members should be told that stopping fluids will not result in patient's immediate death and ordinarily does not hasten death; good oral hygiene is imperative for patient comfort.

Nausea and vomiting

see 1846 (1-5) p., oncological aspects – see 1715 (1-3) p. (oncology)

* many seriously ill patients experience nausea (frequently without vomiting) - GI problems (constipation, gastritis), metabolic abnormalities (hypercalcemia, uremia), drug adverse effects, increased ICP, psychosocial stress.
* if no cause for **mild nausea** is identified → phenothiazine (promethazine, prochlorperazine), anticholinergic (scopolamine), antihistamine (meclizine, diphenhydramine);

second-line drugs for **intractable nausea** - haloperidol, ondansetron and granisetron.

* nausea and pain due to ***intestinal obstruction*** in widespread abdominal cancer:
	+ 1. antiemetics. see 1846 (1-5) p.
		2. hyoscyamine, scopolamine
		3. morphine
		4. octreotide!!! - inhibits GI secretions and dramatically reduces nausea and painful distention, eliminates need for nasogastric suctioning.
		5. **corticosteroids** decrease obstructive inflammation at tumor site and temporarily relieve obstruction.

IV fluids (may exacerbate obstructive edema) and nasogastric suction are not useful in hospice care!

Constipation

- common among dying patients (inactivity, opioids and anticholinergic drugs, decreased intake of fluids and dietary fiber).

Regular bowel movements are essential to comfort of dying patients, at least until last day or two!

Treatment - twice/day ***stool softener*** (e.g. docusate) + mild ***stimulant laxative*** (e.g. casanthranol, senna) or ***osmotic laxative*** (lactulose or sorbitol).

* soft fecal impaction → bisacodyl suppository or saline enema.
* hard fecal impaction → mineral oil enema ± benzodiazepine (e.g. lorazepam) or analgesic, followed by digital disimpaction.

Pressure ulcers

- see 2217 p.

Depression

- experienced by most dying patients.

* providing psychologic support and allowing patients to express concerns and feelings are usually best approach.
* trial of antidepressants is often appropriate for clinically significant depression for patients likely to live beyond 4 wk (needed for onset of antidepressant effect).
* methylphenidate may provide few days or weeks of increased energy for patients who are fatigued or somnolent because of analgesics; but may precipitate agitation.

Last Moments

* can have lasting effect on family members, friends, and caregivers - patient should be in peaceful, quiet, and physically comfortable area.
* *any stains or tubes* on bed should be covered, and *odors* should be masked.
* family members should be encouraged to **maintain physical contact**, such as holding hands, with patient.
* if desired by patient and family members, *presence of friends and clergy* should be encouraged.
* some patients close to death develop ***death rattle*** - noisy bronchial congestion or palatal relaxation; H: scopolamine, hyoscyamine, glycopyrrolate, or diphenhydramine - dry patient's secretions and reduce noise.
	+ turning patient onto one side or into ***semiprone position*** may reduce gurgling; lowering head of bed and raising foot of bed while patient is in semiprone position may cause fluids to move into oropharynx, from which they can be easily removed; oropharyngeal suctioning is not recommended.

Terminal Delirium occurs in some patients at end of life and is considered part of dying process; but exclude urinary retention or pain as reversible cause!

* + some patients prioritize preservation of alertness and ability to communicate with loved ones as long as possible; others prioritize comfort above all else (such patients with *quiet confusion* are less aware of their surroundings and do better with no treatment).
	+ many causes of delirium are potentially reversible with *simple interventions* (such as medication adjustment, providing oxygen, rehydration).
	+ family members and visitors may help lessen confusion by frequently holding patient's hand and repeating where patient is and what is happening.
	+ for agitation, *nonpharmacologic measures* should be instituted (massage, music, relaxation therapies).
	+ **neuroleptics** (such as haloperidol) remains first-line therapy for delirium in terminally ill patients; if more sedation is indicated → short-acting **benzodiazepine** (such as lorazepam or midazolam).
* minimize number of **drugs** that patient is taking; choose least invasive route of administration: buccal mucosa or oral routes → rectal, transcutaneous/transdermal route → SC or IV routes only if necessary; IM route almost never.

After Death

Pronouncement of death

* say something empathic: "I'm sorry for your loss..." or "This must be very difficult for you..."
* physician, nurse, or other authorized person should make official determination of death as quickly as possible to reduce family's anxiety and uncertainty.
1. **identify patient** - use hospital ID tag if available.
2. test for response to **verbal or tactile stimuli** (overtly painful stimuli are not required).
3. listen for absence of **heart sounds**; feel for absence of **carotid pulse**.
4. look and listen for **spontaneous respirations**.
5. record the **position of pupils** and absence of **pupillary light reflex**.
6. ***record time*** at which your assessment was completed.
* provide *comfortable environment* where family members can grieve together, and adequate time for them to be with body.
	+ health professional, usually nurse, should spend a few moments alone in room positioning patient's body, disconnecting any lines and machinery, removing catheters, and cleaning up any mess, to allow family closer access to patient's body.
* do not remove body insensitively or too soon.

Documentation in medical record

1. “**I** was called to pronounce the death of (name) at (**date and time**). **Family / others** noted death at (**date and time**).”
2. findings of **physical examination**.
3. whether **family**, **attending physician**, **coroner** were notified.
4. whether family declines / accepts **autopsy**.

Communicating death via phone

- 6 steps of good communication:

1. **get the setting right** - identify yourself and ask identity of person to whom you are talking and their relationship to patient.
2. **ask what person understands**: "What have you been told about M's condition?"
3. **provide a "warning shot"**: "I'm afraid I have some bad news."
4. **tell the news**: "I'm sorry to have to give you this news, but M just died."
5. **respond to emotions with empathy**: listen quietly to person and allow enough time for information to sink in; elicit questions with phrase like, "What questions do you have?"
6. **conclude with plan**: if family chooses to come to see body, arrange to meet them personally.

Other formal procedures

* family members / funeral directors should be provided with **completed death certificate** as quickly as possible.
* even when death was expected, physicians may need to ***report death to coroner or police***.
* decision about autopsy can be discussed before or just after death.
* organ donation, if appropriate, should be discussed before death or immediately after death; such *discussions are* *sometimes mandated by law*!!!
* for elderly couple, death of one may reveal survivor's cognitive impairment, for which deceased partner had compensated.

Grief

- normal process.

* usually begins before anticipated death.
* family members may need support in expressing grief (up to professional services).

See First Aid Step 1: 20 p.

*Panaudota literatūra*:

“The Merck Manual”, 18th ed., 2005

NMS Introduction to Clinical Medicine 1991