
PALLIATIVE CARE

PART ONE



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TODAY'S TOPIC AREAS

- Definitions and principles
- Ethics and communications
- Giving bad news



WORLD HEALTH ORGANIZATION DEFINITION

Palliative care is an approach that improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable (skillful) assessment and treatment of pain and other suffering; physical, psychosocial and spiritual (edited)

CENTER TO ADVANCE PALLIATIVE CARE

Palliative care, also known as palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

COMMON CONCEPTS IN DEFINITIONS

- serious, life threatening illness
 - treatment focused on providing relief from symptoms, suffering of all kinds
 - whatever the diagnosis
 - used along side curative or aggressive therapies
 - used without curative intent, when no cure can be expected
 - care given by a team, provided to patient and family
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WHAT MAKES UP PALLIATIVE CARE



- Relief of pain and other distressing symptoms
 - psychological and social support for patient and family
 - Anticipation of future events
 - Protection from unwanted or inappropriate medical interventions
 - Multi-disciplinary team
 - Clinician self-care
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WHERE WILL YOU BE PROVIDING PALLIATIVE CARE?

In the home and nursing home

- With family

- With nurses (hospice, palliative care, home nursing)

In the office

- Evaluate and treat

- Training by you and your staff

- Confirm patient is getting the care/medication

In the hospital

- Control severe symptoms

- Manage the last few days of life

Homeless

- A vulnerable population with a high burden of suffering

WHY DO WE PROVIDE PALLIATIVE CARE?

- There is a high prevalence of suffering of all kinds among patients with life-threatening illness
 - All human beings suffer and die
 - Medicine's most fundamental task is not to cure or treat disease, but to comfort suffering human beings
 - Palliative care is a corrective measure for medicine overly focused on specific diseases, organs or molecules
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COMMUNICATION AND ETHICS



WHY ARE ETHICAL PRINCIPLES IMPORTANT IN PALLIATIVE CARE?

- The moral imperative to prevent and relieve suffering is guided by ethical principles
 - These principles increase in importance proportionally with the vulnerability of your patient
 - Palliative medicine deals with the weakest and most vulnerable of patients
 - Thus, ethical principles and guidelines are a particularly important part of palliative medicine
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AUTONOMY AND SHARED DECISION MAKING

- Autonomy may be defined as self-rule by an individual person, free from:
 - Controlling influences by others.
 - Personal limitations such as delirium, dementia, or mental illness.
 - The western principle of autonomy requires that each individual patient be given the respect, opportunity, and information needed to make decisions for himself or herself.
 - the principle of autonomy may still apply in shared decision-making between patients or families and physicians
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BENEFICENCE AND NON-MALEFICENCE

- The principle of beneficence requires the physician to do good for the patient, to help the patient, without regard to personal gain or the interests of other people.
 - The principle of non-maleficence requires the physician to protect the patient from harm.
 - The potential benefits and burdens of all treatments should be weighed prior to initiation and continuously during therapy. Treatments that may sometimes be more burdensome than beneficial include:
 - Chemotherapy or radiation therapy for cancers.
 - Other medications with potentially severe side-effects.
 - Life-sustaining treatments such as mechanical ventilation or hemodialysis.
 - The benefits and burdens of a treatment must be assessed in light of each individual patient's goals, values and beliefs.
 - It is ethical to limit even a life-sustaining treatment if it is deemed more burdensome than beneficial according to the patient's goals, values and beliefs.
 - In western industrialized nations, there is no moral or legal distinction made between withholding (not starting) a life-sustaining treatment and withdrawing a life-sustaining treatment.
 - Therefore, it is ethically acceptable, and often imperative, to withdraw a life- sustaining treatment if it is no longer desired by the patient or is more burdensome than beneficial according to the patient's values.
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PRINCIPLE OF DOUBLE EFFECT

- An ancient doctrine for deciding what to do when any action risks bad effects.
 - It is frequently applied in end-of-life care.
 - If desired by a terminally ill patient, medications intended purely to provide relief from severe pain or other symptoms may be used even at the risk of foreseen but unintended side effects.
 - There are four conditions for applying the principle:
 1. The act itself must not be immoral.
 2. Only the good effect (relief of suffering of a dying patient), not the potential bad side effect (death), may be intended.
 3. The bad effect (death) may not be the means to the good effect (comfort).
 4. The potential benefit of the good effect must outweigh the potential burden of the bad effect (rule of proportionality) (**in the patients eyes**).
 - Examples:
 - High-dose morphine may be given to relieve severe pain or dyspnea even at the risk of foreseeable but unintended sedation, hypotension, respiratory depression, and hastening of death.
 - Near death sedation to relieve intractable suffering may be used even though it may render a patient unconscious until death. (are all four conditions above met in this case?)
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INTENTIONALLY CAUSING THE DEATH OF A PATIENT

Definitions:

Physician Assisted Suicide: The patient commits suicide using medications, information, or other means provided by a physician with the intention of facilitating the suicide.

Euthanasia: The physician performs an action with the intention of directly causing the patient's death.

In western industrialized nations, there is a generally accepted moral and legal distinction between:

Intentionally causing the death of a patient

and

Withholding (not starting) or withdrawing a life-sustaining treatment if it is no longer desired by the patient or if it is more burdensome than beneficial according to the patient's values. In these situations, the patient dies of the disease, not by the hand of the doctor. (dying a natural death, letting nature take its course)

Intentionally causing the death of a patient is illegal in most countries and most US states.

SOME FINAL ETHICAL ISSUES EFFECTING PALLIATIVE CARE

Non-Abandonment

- Withholding or withdrawing life-sustaining treatment or disease-modifying treatment (such as anti-retroviral therapy or cancer chemotherapy) should not result in the patient or family being ignored or abandoned.
- Palliative care, including psychosocial support, can be provided as an alternative.

Duty to Treat

- Most patients, including our families, consider medical professionals to have a duty to treat vulnerable patients who are suffering.
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GOOD PATIENT-PHYSICIAN COMMUNICATION



- Developing a therapeutic alliance
 - Determining the goals of care
 - Shared decision making
 - Patients without decision making capacity
 - Communicating bad news
 - Obtaining informed consent for treatments with risk of bad side effects
 - Responding to requests for physician-assisted suicide or euthanasia
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DEVELOPING A THERAPEUTIC ALLIANCE

- patients do better and patients and families feel better when they:
 - trust the doctor
 - feel respected by the doctor
 - believe the doctor is an ally in the struggle to achieve their medical goals
 - They are more likely to:
 - follow doctors' orders
 - take medications as prescribed
 - return for f/u appointments
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KEY COMPONENTS OF GOOD COMMUNICATION

- Empathy - your empathetic presence can itself comfort a suffering patient and family.
 - Respect - seek to treat each patient as you would want to be treated if you were ill.
 - Trust - first patients need to know that you care. Then they will care what you know.
 - Confidentiality
 - Patients must reveal extremely intimate and potentially embarrassing secrets about themselves to their doctor if the proper diagnosis is to be made and the best treatment found.
 - It is the doctor's responsibility to keep these secrets in the strictest confidence and to reveal them only for the good of the patient (for example to a clinical colleague who can help care for the patient and who is bound by the same commitment to confidentiality).
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DETERMINING THE GOALS OF CARE

Typical goals of care:

Cure (not possible with many cancers, chronic major organ failure, HIV).

Maintain the current or best possible state of health using disease-modifying treatments such as ARV or palliative cancer chemotherapy.

Sustain life with technologies such as mechanical ventilators, cardio-pulmonary resuscitation, and hemodialysis when cardiac arrest or end-stage major organ failure occurs.

Comfort and best possible quality of life.

Some patients will have multiple goals — One goal may take priority over another — Goals usually change over the course of an illness

As more disease-modifying treatments for HIV/AIDS, cancer, and other life-threatening illnesses become available, more patients will suffer from side effects of these treatments and more patients will live longer with severe disabilities such as chronic pain, incontinence, blindness, or paralysis. Therefore, increasingly patients will have to decide about goals of care.

The most important point is that you KNOW YOUR PATIENT'S GOAL(S) for their healthcare.

SHARED DECISION MAKING

Whenever the goal or goals of care are not obvious, it is important to determine them in discussion with the person or persons of the patient's choice as culturally appropriate:

- The patient.
- The family or specific family member(s).
- Sometimes, the patient or family may ask the physician to decide.

Guidelines for discussing goals of care:

- Find out what the patient or decision-maker understands about the illness and prognosis.
 - Find out what the patient or decision-maker is hoping for.
 - Gently educate the patient or decision-maker about the illness and prognosis and correct misconceptions.
 - Since prognosis often is uncertain, provide a range and average.
 - Avoid creating false hope (example: a cure for advanced metastatic lung cancer).
 - Help the patient or decision-maker to set realistic goals.
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IF PATIENT IS WITHOUT DECISION-MAKING CAPACITY

- Does the patient have the ability to understand the information needed to make a decision?
 - Does the patient have the ability to communicate the decision?
 - When a patient lacks the capacity to make or communicate medical decisions for him or herself, a family member or close friend can make decisions for the patient.
 - In western countries, this is called “substituted judgment” by a “surrogate decision-maker.”
 - In wealthy western countries, patients often prepare “advance directives” to facilitate decisions about their care when they are no longer able to decide for themselves. They do this by:
 - Designating a surrogate decision-maker, DPHCA.
 - Preparing a “living will” describing their goals and values and the kind of care they would like under various circumstances.
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COMMUNICATING BAD NEWS

Why is it important to communicate bad news carefully and well?

- You can compound a patient's suffering if it is not done well and in accordance with his or her cultural values.
 - When done well, it strengthens the patient-physician relationship.
 - It allows patients and families to plan realistically and grieve.
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INITIAL PLANNING

- Determine whether the patient would like to receive information herself/himself or whether s/he prefers to designate others such as one or more family members or friends to receive the information.
 - Think in advance about what to say.
 - Allow adequate time.
 - Find a place where you will not be interrupted. Turn off mobile phone.
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SHARING INFORMATION

- Sit down if possible.
 - Ask the patient (or family) if they would like to have others present (for example, other family members, friends, or clinicians) and if they would prefer that someone not be present.
 - Find out what the patient or family understands about the illness and prognosis.
 - Assess the patient's (or family's) ability to comprehend information.
 - Inquire how much the patient (or family) wants to know.
 - Avoid talking too much. Pause frequently to allow the patient or family to react and ask questions and to assess whether your words are being understood.
 - Avoid using medical jargon that patients or families may not understand. Be prepared for a broad range of reactions including anger, sadness, tears.
 - Listen patiently. Express empathy.
 - Plan the next steps
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OBTAINING INFORMED CONSENT

Informed consent is based on the principle of autonomy.

- The patient or surrogate decision-maker requires information about the risks and potential benefits of a specific intervention to make a rational decision whether to accept or decline the treatment.
 - The riskier an intervention, the more important it is to obtain informed consent.
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HOW MUCH INFORMATION TO SHARE

- The amount of information desired by a patient will depend on the patient's culture, beliefs, and values.
 - Some patients may not wish to receive information or make medical decisions, directing that all information be given to someone else such as a family member.
 - Some patients may wish to know everything themselves.
 - There can be a range of beliefs in any country. Don't assume, ask.
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ELEMENTS OF INFORMED CONSENT

- Nature of the intervention.
- Risks (common or severe).
- Potential benefits
- Alternatives.
- Time for the patient or surrogate decision-maker to deliberate (in non-emergent situations).
- Consent (or refusal) should be based on understanding each of these.
- Consent must free of coercion.
- Documentation in the medical record.

Straight forward/low risk (brief)/ Complex/higher risk (longer)

RESPONDING TO REQUESTS FOR PHYSICIAN-ASSISTED SUICIDE OR EUTHANASIA

- Clarify the request with the patient (what exactly is the patient requesting?) by using open-ended questions (to allow the patient to explain what he or she means).
 - Avoid conveying personal biases.
 - Show empathy with words and actions (sit down, speak softly, take extra time).
 - Assess the reason(s) for the request
 - Suffering? (physical, psychological, social, spiritual)
 - Fear? (of future suffering, loss of function, control or dignity, abandonment, being a burden to others)
 - Clinical depression? (usually treatable)
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ASSISTED SUICIDE/EUTHANASIA

CON'T

- Affirm your commitment to care for the patient (non-abandonment)
 - Address the reason for the request as well as possible:
 - Offer to provide or make referrals for palliative care to relieve all types of suffering and many fears.
 - Offer only those services that you know are available (honesty is crucial)
 - Treat clinical depression
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ASSISTED SUICIDE/EUTHANASIA CON'T

- Educate the patient and discuss alternatives
 - Explore with the patient the potential consequences of suicide:
 - To the family.
 - Related to any religious beliefs.
 - Discuss alternatives to physician-assisted suicide or euthanasia:
 - Refusing further disease-modifying or life-sustaining treatments.
 - Reducing or stopping eating.
 - In rare cases of extreme distress refractory to standard palliative interventions, palliative sedation (sedating the patient until death).
 - Explain honestly but compassionately what actions you are and are not willing to take.
 - Consider consulting with colleagues for advice and support while maintaining patient confidentiality
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POST-TEST



1. The more physically, psychologically, or financially vulnerable a patient is, the less relevant ethical principles become.

True

False



2. Major ethical principles in palliative medicine include all of the following except:

1. Social justice
 2. Autonomy
 3. Beneficence
 4. Non-maleficence
 5. Euthanasia
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3. In order to provide the most appropriate treatment, it is necessary to understand the patient's _____ of care.



4. It is important to communicate bad news well because:

- a. It takes less time when done well.
 - b. The patient's suffering can be compounded if it is not done well.
 - c. The patient-physician relationship is strengthened when it is done well.
 - d. All of the above.
 - e. b and c only.
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TOPIC FOR NEXT PC SESSION!

- Pain Assessment and Relief
- Pharmacotherapy for pain
- Pain Cases



Be a dork, embarrass your kids!
