Navigating the Challenges of Palliative/Hospice Care in Home & Other Settings

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Navigating the Challenges of Palliative / Hospice Care in Home & Other Settings

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Percent of U.S. Population by Age Group, 1950-2060

Baby Boomers

PEW RESEARCH CENTER
Leading Causes of Death in USA

- Heart disease
- Cancer
- Chronic lower respiratory diseases
- Stroke (cerebrovascular diseases)
- Accidents (unintentional injuries)
- Alzheimer's disease
- Diabetes
- Nephritis, nephrotic syndrome, and nephrosis
- Influenza and Pneumonia
- Intentional self-harm (suicide)
Challenges of End of Life Palliative and Hospice Care

- Laws, policies, and regulations that affect the organization, financing, and delivery of care

- Attitudes and practices of healthcare providers, including referring physicians and hospice professionals themselves, who are considered "gatekeepers" of the healthcare system

- Consumer misunderstandings, misinformation, and stigmas about hospice care.
Challenges in Palliative & Hospice Care

- Assumptions of care

- Stages of grief and acceptance of the disease and diagnosis

- Communication and relationship with caregivers

- Who’s talking to who?
  - Compartmentalization of roles. Patient, family, professional caregiver - case manager, nurse and doctors
Challenge: Palliative Care

Mrs. B’s Story

- 68 year old white female is transferred to a nursing home after a stroke. Has Living Will/DNR.
- Bed-ridden and cannot communicate because of the stroke. She grimaces if she has pain.
- Placed in palliative care by daughter who is POA.
- Mrs. B develops a severe skin infection (cellulitis) on her leg and foot which, if not treated, will develop gangrene and sepsis.
- The daughter instructs the staff to keep her on Tylenol for pain, no antibiotics, and to hold back on other treatments.
Challenge: Palliative Care

- Palliative team explains to daughter that in palliative care, her mom could receive an antibiotic and Hydrocodone (an opioid pain medication) to keep her mom comfortable.
- If no treatment, they recommend hospice.
- Daughter doesn’t want her mom to become “addicted to pain meds” and refuses hospice.
- Mrs. B dies from sepsis.
- Daughter sues nursing home for negligent care. “No one told me it was that serious.”
Predictable Decline

A greater number of people experience a protracted illness, that ends in a steady inexorable decline in function until death occurs.

As the disease progresses, the clinical condition of the patient ultimately indicates that death is likely in the near term.
Palliative Care

- Palliate from the Latin pallium
  - “Cloak” of protection
  - Medical "to lessen the intensity of a disease"
  - Means to make comfortable by treating a person’s symptoms from an illness to ease (symptoms) without curing the underlying disease

- *Palliative care* can and should be delivered while patients continue treatment for their diseases.

- One of Hospice’s purposes is to ease a dying patient’s pain at the end of life and improve the quality of that life.
Palliative Care

- **Goals of palliative care**
  - improve the quality of a seriously ill person’s life
  - support that person and their family during and after treatment.

- Palliative care may be given at any time during a patient’s illness.

- Can receive antibiotic, continue chemo or have a blood transfusion.
Challenges in Pain Management

Mrs. W’s Story

- 78 year old female with breast cancer and metastatic disease to the bone.

- Opt not to have any further chemotherapy and requests hospice, to be home, and a DNR.

- The daughter, an emergency medical technician (EMT) and her mom’s POA, tells the hospice staff to “keep mom comfortable”.

- Mrs. W. becomes weaker and has increased pain as the cancer spreads to her bones.
Challenges in Pain Management

Mrs. W’s Story

- Because of Mrs. W.’s pain, the hospice physician increases her morphine for relief and comfort.
- Mrs. W. dies approximately 36 hours after the increased dose.
- The daughter feels that the increased morphine killed her mother and sues the hospice for over-medicating her mother.
How do you define comfort?

- Do Nothing
- Do Everything
- Be Placed On Life-Extending Medical Equipment
- Feeding Tube
- Blood Transfusions
- Return to Hospital
- Treat infections
- Medications – for pain, behavior and chronic diseases
Hospice Care

- Hospice focuses on caring, not curing, and is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities.

- Hospice services are available to patients of any age, religion, race, or illness.

- Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.
Hospice Eligibility

• Any person who has a life-threatening or terminal illness.

• Requires a prognosis of six months or less if the illness runs its normal course.

• Patients with both cancer and non-cancer illnesses are eligible to receive hospice care.

• Hospices considers the patient and family together as the unit of care.
Hospice Care

- The majority of hospice patients are cared for in their own residence or with a loved one.

- A family member serves as the primary caregiver and may help make decisions for the terminally ill individual.

- Members of the hospice staff make regular visits to assess the patient and provide additional care or other services.

- Hospice staff is on-call 24 hours a day, seven days a week.
Patients with a terminal disease and any combination of the following symptoms may be eligible for hospice services:

- Pain
- Shortness of breath
- Frequent trips to ER or hospital
- Increased confusion
- Decreased appetite, weight loss
- Infections
- Bed bound / Geri-chair bound / falls
- Decubitus ulcers
- Nausea and/or vomiting
Hospice by the Numbers in the USA

• Hospice care established in U.S. in the 1970s
  • Cancer patients made up the largest percentage of hospice admissions.
  • Today, cancer diagnoses account for less than half of all hospice admissions (36.6%)1
• In the U.S. there were 2.8 million deaths
  • Less than 25% of all U.S. deaths are now caused by cancer
• The top four non-cancer diagnoses
  • Dementia
  • Heart Disease
  • Lung Disease
  • Stroke or Coma
Hospice by the Numbers in the USA

- 4000 hospice care agencies
- 60% of hospice care agencies with for-profit ownership
- Approx. 2.8 million people died in 2014
- 1.3 million admitted to hospice care
- Over 650,000 died while receiving hospice care (the remaining were alive and continued care)
  - which is 25% of people who died in the U.S. of all causes was in hospice.
Mr. C is in the final stages of Alzheimer’s dementia and lives in an assisted living ("AL") home in Tennessee.

The family opts for hospice so he can stay in the AL and not be placed in a nursing home (TN has a waiver for hospice patients in AL).

His sundowning (psychosis symptoms) becomes worse and he is more combative and resists personal care by the staff.
The AL asks the hospice physician for help with behavior and the doctor recommends an anti-anxiety and antipsychotic medication for his behavior.

The wife does not want him medicated because she had read “those medicines will make his heart stop.”

One evening, Mr. C wanders into a female resident’s room and tries to get in bed with her, thinking she is his wife.
The female resident strikes him on the head with a lamp and he is found on the floor, semiconscious, with a laceration to his scalp.

At the hospital, a CAT scan identifies a subdural hematoma.

He dies one week later.


Wife and daughter sue the hospice, the doctor, and the AL for wrongful death.
Documentation

- Documentation should “paint a picture” of why/how the patient is appropriate for hospice as well as the level of care being provided.
- Include education of caregiver about disease
- Should include observations and measurable data, not merely conclusions.
- Documentation should state both facility and hospice staff as to what is said and if understood.
Hospice Team

Hospice care is provided through an interdisciplinary medically directed team.

- Physician
- Nurse
- Home Health Aide
- Social Worker
- Chaplain
- Volunteer
The Hospice Team

Focuses on the dying patient’s needs: physical, psychological, or spiritual.

The goal is to help keep the patient as pain-free as possible, with loved ones nearby until death.

Develops a care plan that meets each patient's individual needs for pain management and symptom control.
Hospice Team

- If appropriate, provides services such as speech and physical therapy when needed

- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time

- Provides bereavement care and counseling to surviving family and friends.
Mr. L is an 81 year old African American male with colon cancer and metastatic disease to the liver and stomach.

He had a history of aspiration from the cancer, depression, hypertension, renal insufficiency and adult failure to thrive.

His daughter is an only child, DPOA, and recently lost her mother to breast cancer.

Mr. L completed chemotherapy with little success. Nothing further was recommended.
Challenge of Hydration and Nutrition
Mr. L’s Story

- He was moved to a rehabilitation facility to “get stronger”.
- Daughter agreed to hospice care after two weeks of no physical therapy progress.
- Mr. L stopped eating because it made him nauseous. He developed a pressure sore.
- The daughter requested a feeding tube be placed so he would get more nutrition.
Challenge of Hydration and Nutrition
Mr. L’s Story

- The hospice discussed not placing the tube because it is a surgical procedure and carries high risk of aspiration.

- Mr. L died ten days later.

- Daughter sued hospice and facility for dehydration, malnutrition and pressure sore.

- It was argued that the refusal of the feeding tube placement hastened his death and that the tube could have prevented the injury issues.
Clinical Nutritional Challenges

- A progressive loss of appetite is a common part of the dying process.

- As the body’s systems slow, the need for caloric intake diminishes.

- Food helped healing in the past may now bring about discomfort and possibly pain.

- Eating and drinking no longer bring pleasure, renewed energy or taste right.

- Skin breakdown is an outward indication of body functions decline.
Clinical Nutritional Challenges

- Over 80 percent of terminal patients have anorexia, or a loss of appetite and most develop cachexia, which is the loss of weight, muscle atrophy, fatigue, weakness and significant loss of appetite.

- Cachexia cannot be reversed nutritionally - even if the number of calories consumed increases, the terminally ill person will continue to lose weight.

- The body’s natural slow-down is a normal process, and is not painful. - do not have an appetite and only want sips or bites of food, or nothing at all.
Documentation

“Documentation to support the terminal illness is an every day, every note practice”
Charting Challenges: Do’s and Don’ts

DO’s

- Have the correct chart before you begin writing.
- Reflects the nursing or physician process, capabilities.
- Write legibly.
- Chart the time of medication, the administration route, and the patient's response.
- Chart precautions or preventive measures used, such as bed rails.
- Record each phone call to a physician, including the exact time, message, and response.
- Chart patient care at the time provided.
- “Late entry” – include the date and time of the late entry.
- Document often enough to tell the whole story.
Charting Challenges: Do’s and Don’ts

Don’ts

- Don't chart a symptom, such as "c/o pain," without also charting what you did about it.
- Don't alter a patient's record - this is a criminal offense.
- Don't use shorthand or abbreviations that aren't widely accepted.
- Don't write imprecise descriptions, such as "bed soaked" or "a large amount."
- Don't chart what someone else said, heard, felt, or smelled unless the information is critical. In that case, use quotations and attribute the remarks appropriately.
- Don't chart care ahead of time - something may happen and you may be unable to actually give the care you've charted. Charting care that you haven't done is considered fraud.
A Natural Death: “AND”  Do Not Resuscitate: “DNR”

- To “Code” a chronically ill person may cause him/her to “die twice”
- AND or DNR does not mean Do Not Treat
- Study from Harvard Medical School
  - Of nursing home patients coded, only 5% had recovery
  - Those who survived had much less mental & physical functioning than before the code.
Allison M. Bungardas JD, MBA, CCM, RN

• Experienced in both Medicare Home Health and Hospice
  • Certified Case Manager
  • Bridging patients between Home Health and Hospice
Reimbursement

- Medicare
  - Benefit periods 90-90-60 days
- Medicaid
  - Minimum of 210 days
- Commercial HMO/PPO
  - Medicare certified agencies
  - Participating provider
  - May have deductibles/co-pays
The Best Laid Plans...

• Even if there is an advanced directives/DNR in place:
  • Patients may feel they are doing the right thing by “hanging on” for their family.
  • Designated advocate does not follow the patient’s directives.
Special Populations

• Pediatrics
• Younger adults with young families
Navigating The Challenges To End of Life Decision-Making

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STATUTORY AUTHORITY

• PATIENT SELF-DETERMINATION ACT (PSDA)
  • ENACTED: 1990
  • REQUIRES hospitals, nursing homes, home health agencies, hospice providers, HMOs, and other health care institutions to:
    • PROVIDE INFORMATION ABOUT ADVANCE HEALTH CARE DIRECTIVES TO ADULT PATIENTS UPON THEIR ADMISSION TO THE HEALTH CARE FACILITY
PATIENT SELF-DETERMINATION ACT (PSDA)

• The requirements of the PSDA are as follows:

• Patients are given written notice upon admission to the health care facility of their decision-making rights, and policies regarding advance health care directives in their state and in the institution to which they have been admitted.
PATIENT SELF-DETERMINATION ACT (PSDA)

• Patient rights include:
  • The right to facilitate health care decisions
  • The right to accept/refuse medical treatment
  • The right to make advance health care directive
PATIENT SELF-DETERMINATION ACT (PSDA)

• Facilities must inquire as to whether the patient already has an advance health care directive, and make note of this in their medical records.

• Facilities must provide education to their staff and affiliates about advance health care directives.

• Health care providers are not allowed to discriminately admit or treat patients based on whether or not they have an advance health care directive.
PATIENT SELF-DETERMINATION ACT (PSDA)

• Purpose of the PSDA

• The purpose of the PSDA is to inform patients of their rights regarding decisions about their own medical care and ensure that their health care provider communicates these rights.

• Specifically, the rights ensured are those of the patient to dictate their future care (by means such as living will or power of attorney), should they ever become incapacitated.
The resident has a right to a dignified existence, self-
determination, and communication with and access to persons and
services inside and outside the facility. A facility must protect and
promote the rights of each resident, including each of the following
rights:
42 C.F.R. § 483.10: RESIDENT RIGHTS

• (b) Notice of rights and services.

• (3) The resident has the right to be fully informed in language that he or she can understand of his or her total health status, including but not limited to, his or her medical condition.

• (4) The resident has the right to refuse treatment, to refuse or to participate in experimental research, and to formulate an advance directive.
42 C.F.R. § 483.10: RESIDENT RIGHTS

• If an adult individual is incapacitated at the time of admission, the facility may give advance directive information to the individual’s family or surrogate in the same manner that it issues other materials about policies and procedures to the family of the incapacitated individual or to a surrogate or other concerned person in accordance with the State law.
(e) Privacy and confidentiality.

The resident has the right to personal privacy and confidentiality of his or her personal and clinical records.

(1) Personal privacy includes accommodations, medical treatment, written and telephone communications, personal care, visits, and meetings of family and resident groups, but this does not require the facility to provide a private room for each resident.

(2) Except as provided in paragraph (e)(3) of this section, the resident may approve or refuse the release of personal and clinical records to any individual outside the facility.
42 C.F.R. § 483.10: RESIDENT RIGHTS

• (j) Access and visitation rights.

• (1) The resident has the right and the facility must provide immediate access to any resident by the following:

  • (iii) The resident’s individual physician;

  • (vii) Subject to the resident’s right to deny or withdraw consent at any time, immediate family or other relatives of the resident; and

  • (viii) Subject to reasonable restrictions and the resident’s right to deny or withdraw consent at any time, others who are visiting with resident consent.
OTHER CONSIDERATIONS/RESOURCES

- Decisions to Forego Life-Sustaining Treatment for Patients Lacking Decision-Making Capacity

- *Advance directives (living wills and durable powers of attorney for health care)* are the best insurance for individuals that their interests will be promoted in the event that they become incompetent.
• *Without an advance directive that designates a proxy, the patient’s family should become the surrogate decision-maker.* Family includes persons with whom the patient is closely associated. In the case when there is no one closely associated with the patient, but there are persons who both care about the patient and have some relevant knowledge of the patient, such persons should be involved in the decision-making process, and may be appropriate surrogates.
OTHER CONSIDERATIONS/RESOURCES

• It is the responsibility of physicians to provide all relevant medical information and to explain to surrogate decision-makers that decisions should be based on substituted judgment (what the patient would have decided) when there is evidence of patients’ preferences and values. If there is not adequate evidence of preferences and values, the decision should be based on the best interests of the patient (what outcome would most likely promote the patient’s well-being).
OTHER CONSIDERATIONS/RESOURCES

• The surrogate’s decision should almost always be accepted by the physician.

• However, there are four situations that may require either institutional or judicial review and/or intervention in the decision-making process. These situations are:
OTHER CONSIDERATIONS/RESOURCES
FOUR SITUATIONS

• When there is no available family member to be the patient’s surrogate decision-maker;

• When there is a dispute among family members and there is no decision-maker designated in an advance directive;

• When a health care provider believes that the family’s decision is clearly not what the patient would have decided if competent; and

• When a health care provider believes that the decision is not a decision that could reasonably be judged to be in a patient’s best interests. Decisions based on conflict of interest generally would not be in a patient’s best interest.
OTHER CONSIDERATIONS/RESOURCES

• In particular, when there are disputes among family members or between family and health care providers, the use of ethics committees specifically designed to facilitate sound decision-making is recommended before resorting to the courts.

• Judicial review for decisions about life-sustaining treatment should be a last resort. It is strongly encouraged that when judicial review is necessary, in nonemergency situations, the courts should determine who is to make treatment decisions, including appointing a guardian, rather than actually making treatment decisions.
OTHER CONSIDERATIONS/RESOURCES

- When a permanently unconscious patient was never competent or had not left any evidence of previous preference or values, since there is no objective way to ascertain what would be in the best interests of the patient, the surrogate’s decision should not be challenged as long as the decision is based on the decision-maker’s true concern for what would be best for the patient.
KEY AREAS RELATED TO ADVANCE DIRECTIVES

• CONTENTS OF HEALTH CARE DIRECTIVE
• PRESENCE OF DNR-DNI SIGNED DOCUMENT
• PROVIDER ORDERS FOR LIFE-SUSTAINING TX (POLST)
• FACILITY POLICIES RE CPR, POLST, ADVANCE DIRECTIVES
• PATIENT/RESIDENT PHYSICAL AND MENTAL STATUS
HEALTH CARE DIRECTIVE-LIVING WILL

• Defines decision-making capacity.

• States that principal must have decision-making capacity to execute a health care directive.

• States that principal who has decision-making capacity can revoke a health care directive.

• States that a court has the power to declare a health care directive unenforceable.

• Includes the presumption that a principal is presumed to have the capacity to execute a health care directive and to revoke it absent clear and convincing evidence to the contrary and related presumptions.
DNR/DNI GUIDELINES

• **Purpose of Form**: to allow an individual the option of limiting emergency care when appropriate. The goal is to provide consistent language and documentation between a hospital, LTC facility, home health care setting, other setting, and emergency providers. The document may be used in any setting where emergency care is needed.

• **Legality of Form**: The DNR/DNI form is a legal document, with MD involvement, and it directs health care providers in responses to emergency calls. The patient has the right to revoke the restrictions at any time. MD signature is required.
DNR/DNI GUIDELINES

• The MD should document in the patient’s permanent record:

• Rationale for DNR or comfort care that includes DNR

• Basis for determining patient competency

• Significant parties involved in the decision and their relationship to the patient
POLST: PROVIDER ORDERS FOR LIFE-SUSTAINING TREATMENT

• Why a POLST?
  • Patient lacks capacity to make health care decision

  • HCD has had very limited success:

    • Many patients have not completed one
      • Most advance directives unavailable when needed
      • Advance directives are often vague

  • It provides opportunity for families to ask questions of providers and make wishes known
POLST: PROVIDER ORDERS FOR LIFE-SUSTAINING TREATMENT

• Protects and promotes patient autonomy better than advance directives

• It addresses patient current vs. future potential situations and is created with a medical provider—more relevant to patient condition/needs

• POLST form is portable and transports with patient-available

• It is written in precise medical language—better understood

• It is signed by a provider, making it have greater chance of compliance by other provider
POLST: PROVIDER ORDERS FOR LIFE-SUSTAINING TREATMENT

• Who can sign the POLST?

• When is the POLST reviewed?

• What if the POLST conflicts with an Advance Directive?
Duties of Health Care Providers regarding the POLST?

- Health care providers must comply with signed POLST.
- If health care provider is unwilling to comply with POLST the provider must take all reasonable steps to transfer patient to another MD/provider.
- POLST must be honored even if provider who signed it does not have admitting privileges.
- There is a duty to comply with POLST completed in another state, provided the forms comply with the laws of the treating state.
DETERMINING PRINCIPAL DECISION-MAKING CAPABILITY & WHEN AGENT HAS AUTHORITY TO ACT

- **Determining Decision-making Capacity**

  The determination of capacity is a medical decision, which has significant legal impact, and allows little influence from the legal community. A functional assessment using a recognized assessment tool is currently the standard for determining capacity to consent to treatment and is endorsed by the ABA.
DETERMINING PRINCIPAL DECISION-MAKING CAPABILITY & WHEN AGENT HAS AUTHORITY TO ACT

Determining Decision-making Capacity

• THE LAWYER SHOULD CONSIDER:

• (1) client’s ability to articulate reasoning leading to a decision;

• (2) variability of state of mind and ability to appreciate consequences of a decision;

• (3) the substantive fairness of a decision; and

• (4) the consistency of a decision with the known long-term commitments and values of the client.

• If the lawyer thinks it is appropriate after consideration of these factors, she should seek guidance from an appropriate diagnostician to determine a client’s level of diminished capacity.
DETERMINING PRINCIPAL DECISION-MAKING CAPABILITY & WHEN AGENT HAS AUTHORITY TO ACT

DETERMINING DECISION-MAKING CAPACITY

• OTHER FACTORS TO CONSIDER:

  • PATIENT’S PHYSICAL CONDITION
  • EXPECTATION FOR RECOVERY
  • PATIENT’S PAIN & MEDICATION
  • HEALTH CARE DIRECTIVE’S AGENT
DETERMINING PRINCIPAL DECISION-MAKING CAPABILITY & WHEN AGENT HAS AUTHORITY TO ACT
USE OF SURROGATES

• Surrogate Designation

• Patient-Designated Surrogate in an Advance Directive
• Physician-Designated Surrogate: Default Surrogates & Proxies
• Court-Designated Surrogates: Guardians and Conservators
DETERMINING PRINCIPAL DECISION-MAKING CAPABILITY & WHEN AGENT HAS AUTHORITY TO ACT USE OF SURROGATES

• Surrogate Duties

• Substituted Judgment: Implement Patient’s Preferences
• Subjective Standard: Implement Patient Instructions
• Best Interests Standard: Promote the Patient’s Welfare
DETERMINING PRINCIPAL DECISION-MAKING CAPABILITY & WHEN AGENT HAS AUTHORITY TO ACT
WHO IS THE SURROGATE

- Conservator
- Guardian
- Power of Attorney
CONFLICTS ARISE: PATIENT CONFIDENTIALITY VS. FAMILY INFORMATION & HEALTH CARE PROVIDERS PREPARING HCDs

• WHAT TO DO WHEN POTENTIAL CONFLICTS ARISE
• Objectives

• To identify the nature of conflict
• To identify the cost of conflict
• To identify the causes of conflict in end-of-life care
• To demonstrate skill in subverting conflict in the early stages
• To describe techniques for third party mediation in end-of-life care
CONFLICTS ARISE: PATIENT CONFIDENTIALITY VS. FAMILY INFORMATION & HEALTH CARE PROVIDERS PREPARING HCDs

• End of Life Decisions  Create Conflict
• Causes of Conflict
• Price of Conflict with Families
• The Inevitably of Conflict
• Skills for Conflict Resolution
• Test the Choices for Outcome
Navigating The Challenges To End of Life Decision-Making

THANK YOU
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