CHANGING THE TRAJECTORY: *HOW PALLIATIVE CARE IMPROVES QUALITY OF LIFE ACROSS THE CARE CONTINUUM*

Health Ministries Association

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PRAY

WHAT I AM HOPING YOU WILL LEARN TODAY

1. Differentiate between hospice care and palliative care
2. Describe how palliative care can significantly improve quality of life for patient, family and caregiver(s
3. Discuss how palliative care may transition to hospice care as condition and goals change.
4. Describe how the Faith Community Nurse fits into the palliative and hospice care dynamic.

WHERE ARE YOU FROM?

WHY ARE YOU HERE TODAY?

WHAT QUESTIONS DO YOU HAVE?

PARTNER UP!!!

OHIO DEPARTMENT OF HEALTH: CHRONIC DISEASES AND CONDITIONS

- https://odh.ohio.gov/wps/portal/gov/odh/home
- https://odh.ohio.gov/wps/portal/gov/odh/know-our-programs/chronic-disease/chronic-disease-conditions
- https://odh.ohio.gov/wps/wcm/connect/gov/b15bfd2e-a543-4c08-83ec-37378d10fb2d/CD+Burden+Final_Web.pdf?MOD=AJPERES&CONVERT_TO=url&CACHEID=ROOTWORKSPACE.Z18_M1HGGIK0N0JO00QO9DDDDM3000-b15bfd2e-a543-4c08-83ec-37378d10fb2d-mthHMug

COSTS OF HEALTH CARE WITH A LIFE LIMITING ILLNESS

- The National Cancer Institute estimates that the cost of cancer care will exceed $174 billion in 2020 due to growing numbers of cancer survivors and the aging US population
- The U.S. healthcare system, including hospice and palliative care, will be impacted by:
  - A burgeoning elderly population estimated to increase to more than 72 million by 2030,3
  - The cost of healthcare at the end of life,
  - A projected physician shortage of as much as 120,000 by 2030,4 and
  - A significant shortfall in the number and availability of paid and family caregivers that exists now and will only worsen in the near future.5

[Accessed February 7, 2017];Cancer Prevalence and Cost of Care Projections. https://costprojections.cancer.gov/

Accessed 10/6/19; Is end-of-life care threatened by today's healthcare environment? https://www.ohioshospice.org/is-end-of-life-care-threatened-by-todays-healthcare-environment/

ECONOMICS OF PALLIATIVE CARE FOR HOSPITALIZED ADULTS WITH SERIOUS ILLNESS

- Meta-analysis from patients 2013-2017 most common healthcare data bases searched and studies with 133 118 patients
- Hospitalized adults with at least 1 of 7 illnesses (cancer; heart, liver, or kidney failure; chronic obstructive pulmonary disease; AIDS/HIV; or selected neurodegenerative conditions) International study
- With palliative care vs usual care only, controlling for a minimum list of confounders

May, P., Normand, C., Cassel, J. B., Del Fabbro, E., Fine, R. L., Menz, R., … Morrison, R. S. (n.d.). Economics of Palliative Care for Hospitalized Adults With Serious Illness A Meta-analysis. JAMA INTERNAL MEDICINE, 178(6), 820–829. https://doi-org.cedarville.ohionet.org/10.1001/jamainternmed.2018.0750

FINDINGS

- *"The study, Economics of Palliative Care for Hospitalized Adults With Serious Illness, found when palliative care was added to a patient's treatment, hospitals saved an average of $3,237 per patient over the course of a hospital stay compared to patients who did not receive palliative care. Additionally, for cancer patients, hospitals saved an average of $4,251 per stay. For non-cancer patients, hospitals saved an average of $2,105 per stay."*

Lardieri, A. (2018). Study: Palliative Care Reduces Hospital Stay, Cost of Sickest Patients. Retrieved 10/6/19 https://www.usnews.com/news/health-care-news/articles/2018-04-30/study-palliative-care-reduces-hospital-stay-cost-of-sickest-patients

HISTORY OF HOSPICE CARE

- https://www.youtube.com/watch?v=I_2WscrOhB4

WHAT IS PALLIATIVE CARE?

https://www.youtube.com/watch?v=IDHhg76tMHc

WHAT ARE DEFINITIONS OF PALLIATIVE CARE?

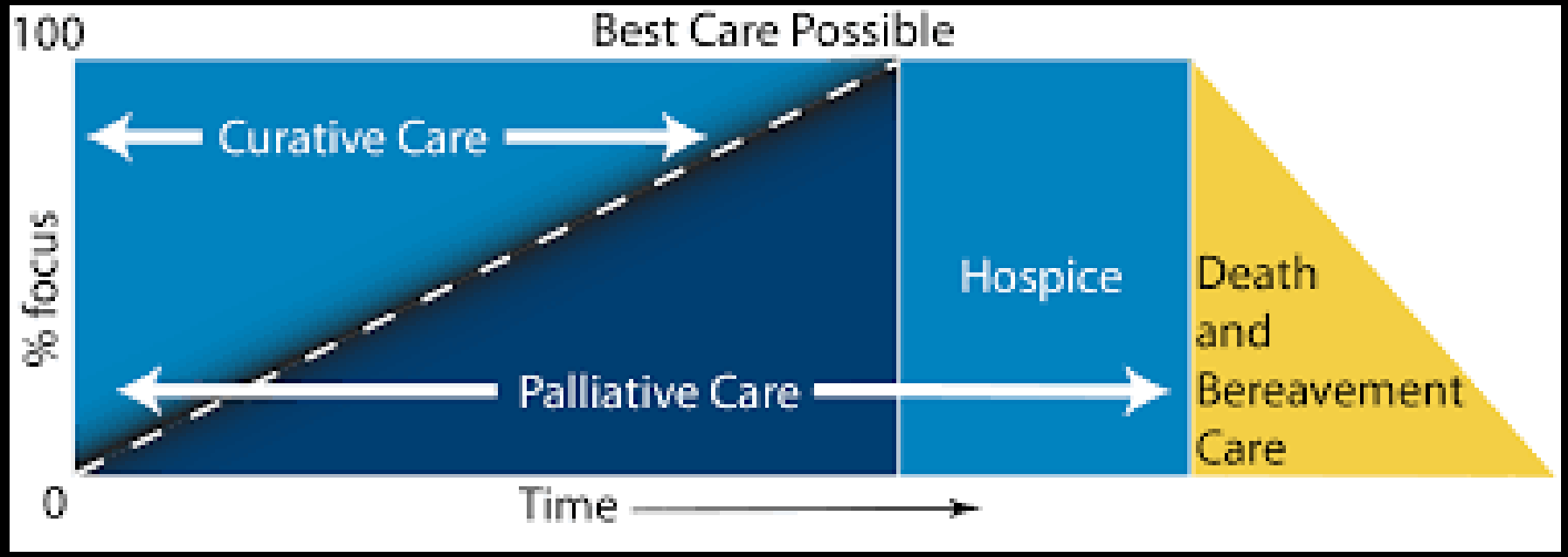
Who publishes definitions of palliative care?

LET'S HEAR FROM THE LEAD PALLIATIVE CARE PHYSICIAN IN THE UNITED STATES-DR. DIANE MEYER

Dr. Diane Meyer describes difference between palliative care and hospice

SO, THEN WHAT TYPES OF HEALTH CHALLENGES/ILLNESSES ARE APPROPRIATE TO HAVE PALLIATIVE CARE?

PALLIATIVE CARE MODEL



Retrieved 11/6/2016 from milwakee.va.gov

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The Education in Palliative and End-of-life Care program at Northwestern University Feinberg School of Medicine, created with the support of the American Medical Association and the Robert Wood Johnson Foundation

Module 1

Advance Care Planning

Objectives ...

- Define advance care planning and explain its importance
- Distinguish between types of advance directives
- Describe the role of the patient, surrogate and health care providers

... Objectives

- Describe the five steps for successful advance care planning
- Identify pitfalls and limitations in advance care planning

Clinical case

Advance care planning…

- Process of planning for future medical care at a time when person is no longer capable of making health care decisions
- Values and goals are explored, documented
- Surrogate decision maker is named

… Advance care planning

- Builds trust
- Reduces uncertainty
- Helps to avoid confusion and conflict
- Permits peace of mind

… Advance care planning

- Builds trust
- Reduces uncertainty
- Helps to avoid confusion and conflict
- Permits peace of mind

Advance directive

- Written statement
- By a person who has decision making capacity
- Regarding preferences about future health care decisions
- In the event that the individual becomes unable to make decisions

Types

- Durable Power of Attorney for Health Care – surrogate is designated
- Living Will – personal preferences regarding future treatment options are indicated
- State-authorized advance directive – advance directive document legally recognized by particular state

Role of the patient

THINK – TALK – WRITE – REVIEW

- **Ask questions, consult, discuss**
- **Express preferences for surrogate decision-maker and/or future care**
- **Sign advance care planning document**
- **Revise or revoke previously executed documents**

Role of the surrogate

- Surrogate = person who is authorized to make health care decisions when patient lacks decision-making capacity
  - ask questions
  - keep a copy of advance care planning documents
  - be ready to serve as surrogate decision-maker and follow the patient's preferences

Role of the clinicians

- Five steps for successful advance care planning
  - initiate
  - educate
  - discuss and/or refer
  - document
  - revisit

Step 1: Initiate …

- Who
- When
- Where

… Step 1: Initiate

- What
  - assess patient's current knowledge of advance care planning
  - inquire if patient has an advance directive
- Review any existing advance directives
- Reconcile any multiple advance care planning documents

Step 2: Educate …

- Explain what an advance directive is
- Explain benefits of advance directives
- Explain limitations of advance directives

… Step 2: Educate

- Encourage patient to appoint a Health Care Agent through a Durable Power of Attorney for Health Care document
- Encourage patient to involve loved ones
- Educate patient about available resources

Step 3: Discuss / Refer

- Assist in completing worksheets
- Refer if patient has questions you cannot answer
- Refer for help in completing advance care planning document(s)

Step 4: Document

- Document advance care planning discussion
- Document completion of advance directive

Step 5: Revisit

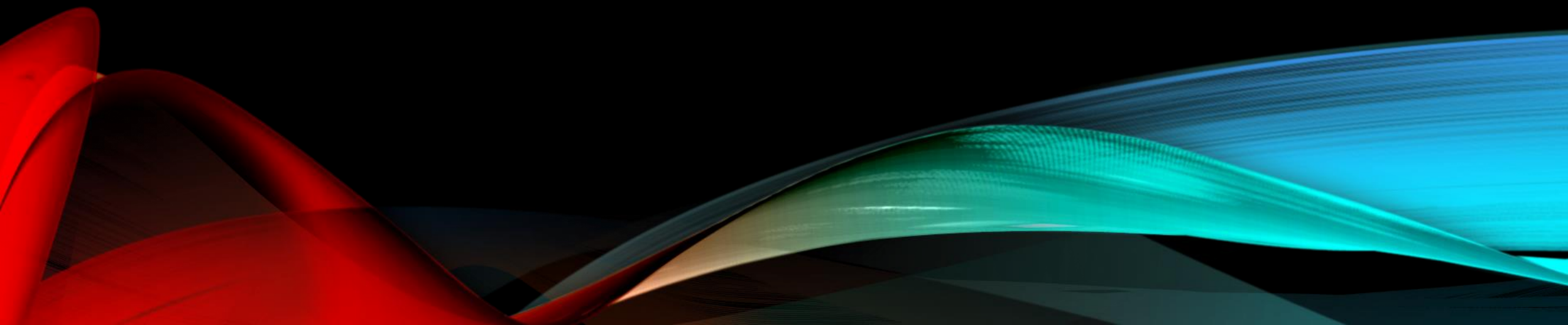
- Who
- When
- Where
- What

Challenges in advance care planning

- Avoidance
- Failing to clarify patient preferences
- Focusing discussion too narrowly
- Ignoring patients who are communication-impaired
- Assuming the content of the advance directive

Summary

WHERE DO WE GET ADVANCE DIRECTIVES DOCUMENTS IN OHIO?



ADVANCE DIRECTIVES CLEVELAND CLINIC PATIENT EDUCATION

http://my.clevelandclinic.org/patients-visitors/legal-ethical-decisions/personal-medical-decisions/advance-directives

OHIO ADVANCE DIRECTIVES FORMS

https://ohiohospitals.org/getmedia/9d65b1eb-2dd0-4678-b59e-e8059b226f39/Ohio-Advance-Directives-Forms.pdf.aspx

PALLIATIVE CARE FAST FACTS

http://www.mypcnow.org/fast-facts

FAMILY MEETING & BREAKING BAD NEWS

Palliative Care Fast Facts #222-227-Family Meeting

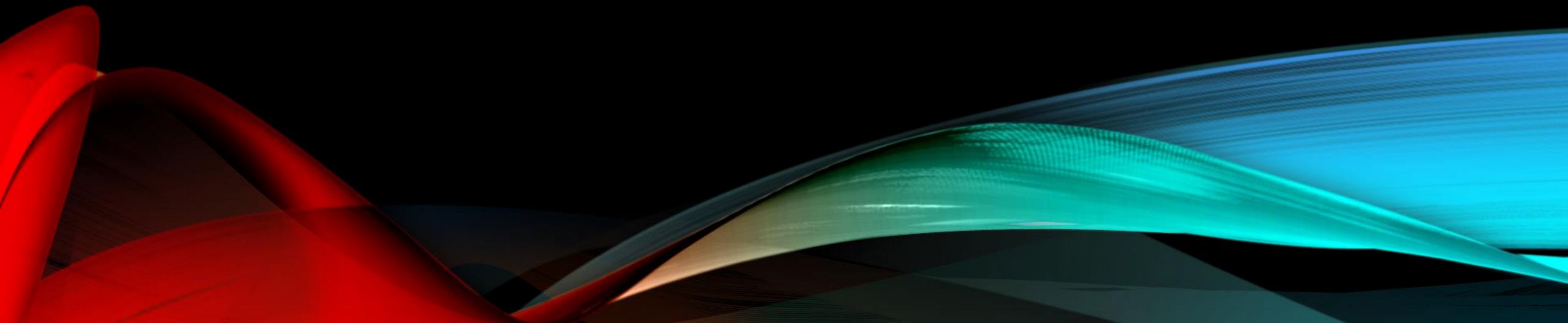
Palliative Care Fast Facts #6 & 11

FAMILY MEETING FROM THE EXPERT

https://www.youtube.com/watch?v=7kQ3PUyhmPQ

LET'S TRY IT

We will design our own case



HOW COULD A FAITH COMMUNITY NURSE BE A PALLIATIVE CARE ADVOCATE?

NEVER LET THEM BE SURPRISED!

PRAY

HOW COULD A FAITH COMMUNITY NURSE BE A PALLIATIVE CARE ADVOCATE?

- EARLY PALLIATIVE CARE
  - FACILITATE UNDERSTANDING OF DISEASE
  - FACILITATE FAMILY MEETING-GOALS OF CARE
  - FACILITATE CONTINUUM OF CARE-"KNOW THE STORY"
  - ASSURE HOLISITIC ASSESSMENT
  - INTRODUCE AND COMPLETE ADVANCE CARE PLANNING IF POSSIBLE

PRAY!

HOW COULD A FAITH COMMUNITY NURSE BE A PALLIATIVE CARE ADVOCATE?

- MIDDLE PALLIATIVE CARE
  - FACILITATE UNDERSTANDING OF DISEASE
  - ASSURE ADVANCE DIRECTIVES COMPLETION
  - FACILITATE FAMILY MEETING-GOALS OF CARE
  - FACILITATE CONTINUUM OF CARE-"KNOW THE STORY"
  - ASSURE HOLISITIC SYMPTOM MANAGEMENT

  PRAY!

HOW COULD A FAITH COMMUNITY NURSE BE A PALLIATIVE CARE ADVOCATE?

- TRANSITION FROM SOLEY PALLIATIVE CARE TO HOSPICE CARE
  - Recognize early the time for transition and help support
  - Help family brain storm possible hospice options for care
  - Education and emotional support during the ACTUAL TRANSITION

Did I mention PRAY?

HOW COULD A FAITH COMMUNITY NURSE BE A PALLIATIVE CARE ADVOCATE?

- END OF LIFE CARE
  - APPROPRIATE INTRODUCTION WITH HOSPICE TEAM
  - COLLABORATE ON BEHALF OF PATIENT AND FAMILY WITH HOSPICE TEAM
  - COLLABORATE ON BEHALF OF THE HOSPICE TEAM TO THE PATIENT/FAMILY
  - ASSURE SYMPTOM MANAGEMENT
  - ASSURE IMPORTANT VISITS ARE COMPLETE
  - ASSURE IMPORTANT RELATIONSHIP HEALING IS OFFERED
  - ASSURE POTENTIAL REMEMBRANCE ACTIVITIES ARE COMPLETE
  - ASSURE SPIRITUAL CARE AND RITUALS ARE COMPLETE
  - PRAY PRAY PRAY PRAY PRAY!!!!!!!!!!!!!!!!!!

HOW COULD A FAITH COMMUNITY NURSE BE A PALLIATIVE CARE ADVOCATE?

- BEREAVEMENT CARE
  - ASSURE GRIEF COUNSELING IS OFFERED
  - ENCOURAGE COLLABORATION WITH PCP
  - ASSURE CONNECTION WITH HOSPICE BEREAVEMENT PROGRAM
  - PAY ATTENTION TO SIGNIFICANT DATES

TAKE CARE OF YOURSELF AND SET APPROPRIATE BOUNDARIES

YOUVERSION

QUESTIONS???

THANK YOU FOR YOUR ATTENTION

PART 2-ANY THOUGHTS?

Kettering Health Network

May 25, 2018 and June 1, 2018

Beth Delaney, MS, RN, CNS, FNP-BC, OCN, ACHPN, DNP

WORSHIP

- https://www.youtube.com/watch?v=PqqtyuivolA&list=PL9097D8DC3AAF079B&index=55
- Worship and music
  - Inspiration
  - Healing
  - Encouragement
  - Healthy Coping

WHAT I AM HOPING YOU LEARN TODAY

- More Healthy Coping Strategies…it is sometimes hard to be a nurse
- How to structure a family meeting and Break Bad News using Palliative Care Fast Facts
- 5 Ethical Principles related to End of Life Care and how to access the ethics process at KHN
- Principles of Withdrawing from Life Sustaining Treatment
- Principles of End of Life Care
- The Purple Book Resource

- TODAY IS CONTENT AND RESOURCE HEAVY

WHAT WENT WELL THE LAST 2 WEEKS?

WHAT DID NOT GO WELL THE LAST 2 WEEKS?

WHAT DID YOU WISH YOU KNEW AND DIDN'T IN THE LAST 2 WEEKS?

LET'S NOT FORGET THIS

http://www.ketteringhealth.org/aboutus/history.cfm

THEREFORE, WITH YOUR HERITAGE AND GOD NOTHING IS IMPOSSIBLE

“Jesus looked at them and said, "With man this is impossible, but with God all things are possible.“ Matthew 19:26 New International Version

BACK TO OUR CASE

- From last time…how do we prepare for a family meeting?
- 2 Different Resources
  - Palliative Care Fast Facts #222-227-Family Meeting
  - Palliative Care Fast Facts #6 & 11-Breaking Bad News
  - OR
  - EPEC-the slides are next

- LET"S TRY IT OUT

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Module 2

Communicating Difficult News

Objectives

- Know why communication of “difficult” news is important
- Understand the 6-step protocol for delivering difficult news

Importance

- Most people want to know
- Strengthens clinician-patient relationship
- Fosters collaboration
- Permits patients, families to plan, cope

6-step protocol ...

1. Getting started
2. What does the patient know?
3. How much does the patient want to know?

Adapted from Robert Buckman

... 6-step protocol

4. Sharing the information
5. Responding to patient, family feelings
6. Planning and follow-up

Adapted from Robert Buckman

Step 1: Getting started ...

- Plan what you will say
  - confirm medical facts
  - don’t delegate
- Create a conducive environment

… Step 1: Getting started

- **Allot adequate time**
  - **prevent interruptions**
- **Determine who else the patient would like present**
- **Determine what team members will be present**

Step 2: What does the patient know?

- Establish what the patient knows
- Assess ability to comprehend new bad news
- Reschedule if unprepared

Step 3: How much does the patient want to know? ...

- Recognize, support various patient preferences
  - decline voluntarily to receive information
  - designate someone to communicate on his or her behalf

… Step 3: How much does the patient want to know?

- **People handle information differently**
  - **race, ethnicity, culture, religion, socioeconomic status**
  - **age and developmental level**

When family says “don’t tell” …

- Legal obligation to obtain informed consent from the patient
- Promote congenial family alliance
- Honesty and transparency promotes trust

… When family says “don’t tell”

- **Ask the family:**
  - **Why not tell?**
  - **What are you afraid I will say?**
  - **What are your previous experiences?**
  - **Is there a personal, cultural, or religious context?**
- **Talk to the patient together**

Step 4: Sharing the information ...

- **Say it, then stop**
  - **avoid monologue, promote dialogue**
  - **avoid jargon, euphemisms**
  - **pause frequently**
  - **check for understanding**
  - **use silence, body language**

… Step 4: Sharing the information

- Don’t minimize severity
  - avoid vagueness, confusion
- Implications of “I’m sorry”

Step 5: Responding to feelings ...

- **Affective response**

  tears, anger, sadness, love, anxiety, relief, other

- **Cognitive response**

  denial, blame, guilt, disbelief, fear, loss, shame, intellectualization

… Step 5: Responding to feelings …

- Be prepared for
  - outburst of strong emotion
  - broad range of reactions
- Give time to react

... Step 5: Responding to feelings

- Listen quietly, attentively
- Encourage descriptions of feelings
- Use nonverbal communication

Step 6: Planning, follow-up ...

- Plan for the next steps
  - additional information, tests
  - treat symptoms, referrals as needed
- Discuss potential sources of support

... Step 6: Planning, follow-up

- Give contact information, set next appointment
- Before leaving, assess:
  - safety of the patient
  - supports at home
- Repeat news at future visits

When language is a barrier ...

- Use a skilled interpreter
  - familiar with medical terminology
  - comfortable translating bad news
- Consider telephone translation services

… When language is a barrier

- Avoid family as primary interpreter
  - confuses role of family members
  - may not know how to translate medical concepts
  - may modify news to protect patient
  - may supplement the translation
- Speak directly to the patient

Communicating prognosis ...

- Some patients want to plan
- Others are seeking reassurance

… Communicating prognosis …

- Inquire about reasons for asking
  - “What are you expecting to happen?”
  - “How specific do you want me to be?”
  - “What experiences have you had with:
    - others with same illness?
    - others who have died?”

… Communicating prognosis …

- **Patients vary**
  - **“planners” want more details**
  - **those seeking reassurance want less**
- **Avoid precise answers**
  - **use ranges: hours to days … months to years**
  - **average**

… Communicating prognosis

- **Limits of prediction**
  - **hope for the best, plan for the worst**
  - **better sense over time**
  - **can’t predict surprises**
- **Reassure availability, whatever happens**

Caregiver communication

- Maintain common chart or log book
  - goals for care
  - treatment choices
  - what to do in an emergency
  - things to do / not to do
  - contact information

ETHICS IN END OF LIFE AND PALLIATIVE CARE

- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2902121/

THE HASTINGS CENTER

- Who they are
  - http://www.thehastingscenter.org/who-we-are/
- Partner UP
  - http://www.thehastingscenter.org/wp-content/uploads/End-of-Life-Care-BB11.pdf
    - Read the short 4 page document
    - Tell your partner 2 things that you learned
    - Tell them one thing you were surprised about
    - Name one ethical issue

WITHDRAWAL OF LIFE SUSTAINING TREATMENT PRINCIPLES

EPEC review

EPEC

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Module 11

Withholding, Withdrawing Life-Sustaining Treatments

Objectives

- Know the principles for withholding or withdrawing therapy
- Apply these principles to the withholding or withdrawal of
  - artificial feeding, hydration
  - ventilation
  - cardiopulmonary resuscitation

Role of the clinician. . .

- The clinician helps the patient and family
  - elucidate their own values
  - decide about life-sustaining treatments
  - dispel misconceptions
- Understand goals of care
- Facilitate decisions, reassess regularly

. . . Role of the clinician

- Discuss alternatives
  - including palliative and hospice care
- Document preferences, medical orders
- Involve, inform other team members
- Assure comfort, nonabandonment

Legal Perspective

- Karen Quinlan (1976)
- Nancy Cruzan (1990)
- Terrie Schiavo (2005)

Common concerns

- Legally required to “do everything?”
- Is withdrawal, withholding euthanasia?
- Can the treatment of symptoms constitute euthanasia?
- Is the use of substantial doses of opioids euthanasia?
- Aren’t withholding and withdrawing interventions very different?

Life-sustaining treatments

- Resuscitation
- Elective intubation
- Surgery
- Dialysis
- Blood transfusions, blood products
- Diagnostic tests
- Artificial nutrition, hydration
- Antibiotics
- Other treatments
- Future hospital, ICU admissions

6-step protocol to discuss treatment preferences . . .

1. Be familiar with policies, statutes
2. Ask the patient, family what they understand
3. Discuss general goals of care
4. Discuss specific treatment preferences

. . . 6-step protocol to discuss treatment preferences

5. Respond to emotions
6. Review and revise

Example 1: Artifical feeding, hydration

- Difficult to discuss
- Food, water are symbols of caring
- Establish overall goals of care
- Will artificial feeding, hydration help achieve these goals?

Address misperceptions

- Cause of poor appetite, fatigue
- Relief of dry mouth
- Delirium
- Urine output

Help family with need to give care

- Identify feelings, emotional needs
- Identify other ways to demonstrate caring

  teach the skills they need

Normal dying

- Loss of appetite
- Decreased oral fluid intake
- Artificial food / fluids may make situation worse
  - breathlessness
  - edema
  - ascites
  - nausea / vomiting

Example 2: Ventilator withdrawal

- Rare, challenging
- Ask for assistance
- Assess appropriateness of request
- Role in achieving overall goals of care

Immediate extubation

- Remove the endotracheal tube after appropriate suctioning
- Give humidified air or oxygen to prevent the airway from drying
- Ethically sound practice

Prepare the family . . .

- Describe the procedure
- Reassure that comfort is a primary concern
- Medication is available
- Patient may need to sleep to be comfortable

. . . Prepare the family

- Involuntary movements
- Provide love and support
- Describe uncertainty

Ensure patient comfort

- Anticipate and prevent discomfort
- Have anxiolytics, opioids immediately available
- Titrate rapidly to comfort
- Be present to assess, reevaluate

Prevent symptoms

- **Breathlessness**
  - **opioids**
- **Anxiety**
  - **benzodiazepines**

Preparing for ventilator withdrawal

- Determine degree of desired consciousness
- Bolus 2-20 mg morphine IV, then continuous infusion
- Bolus 1-2 mg midazolam IV, then continuous infusion
- Titrate to degree of consciousness, comfort

Prior to withdrawal

- Prior to procedure
  - discussion and agreement to discontinue
    - with patient (if conscious)
    - with family, nurses, respiratory therapists
  - document on the patient’s chart

Withdrawal protocol– part 1

- Procedure
  - shut off alarms
  - remove restraints
  - NG tube is removed
  - family is invited into the room
  - pressors are turned off
  - parents may hold child

Withdrawal protocol– part 2

- Establish adequate symptom control prior to extubation
- Have medications in hand
  - midazolam, lorazepam, or diazepam
- Set FiO_2 to 21%
- Adjust medications
- Remove the ET tube

Withdrawal protocol– part 3 . . .

- Invite family to bedside
- Washcloth, oral suction catheter, facial tissues
- Reassess frequently

. . . Withdrawal protocol– part 3

- After the patient dies
  - talk with family and staff
  - provide acute grief support
- Offer bereavement support to family members
  - follow up to ensure they are okay

Example 3: Cardiopulmonary resuscitation…

- Establish general goals of care
- Use understandable language
- Avoid implying the impossible
- Ask about other life-prolonging therapies
- Affirm what you will be doing

. . . Example 3: Cardiopulmonary resuscitation

- Discuss in context of the goals of care
- Provide information about probability of success relative to those with similar conditions
- The decision to forego CPR does not presume a decision to forego other life-sustaining treatments

Write appropriate medical orders

- DNR/DNAR
- DNI
- Do not transfer
- POLST

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- More Healthy Coping Strategies…it is sometimes hard to be a nurse
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EPEC

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Module 12

Last Hours of Living

Objectives

- Prepare, support the patient, family, caregivers
- Assess, manage the pathophysiological changes of dying
- Pronounce a death and notify the family

Last hours of living

- Everyone will die
  - < 10% suddenly
  - > 90% prolonged illness
- Unique opportunities and risks
- Little experience with death
  - exaggerated sense of dying process

Preparing for the last hours of life …

- Time course unpredictable
- Any setting that permits privacy, intimacy
- Anticipate need for medications, equipment, supplies
- Regularly review the plan of care

… Preparing for the last hours of life

- Caregivers
  - awareness of the veteran's choices
  - knowledgeable, skilled, confident
  - rapid response
- Likely events, signs, symptoms of the dying process

Physiological changes during the dying process

- Increasing weakness, fatigue
- Cutaneous ischemia
- Decreasing appetite / fluid intake
- Cardiac, renal dysfunction
- Neurological dysfunction
- Pain
- Loss of ability to close eyes

Weakness / fatigue

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

Decreasing appetite / food intake

- Fears: “giving in,” starvation
- Reminders
  - food may be nauseating
  - anorexia may be protective
  - risk of aspiration
  - clenched teeth express desires, control
- Help family find alternative ways to care

Decreasing fluid intake ...

- Oral rehydrating fluids
- Fears: dehydration, thirst
- Remind families, caregivers
  - dehydration does not cause distress
  - dehydration may be protective

... Decreasing fluid intake

- **Parenteral fluids may be harmful**
  - **fluid overload, breathlessness, cough, secretions**
- **Mucosa / conjunctiva care**

Cardiac, renal dysfunction

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

Changes in respiration ...

- Altered breathing patterns
  - diminishing tidal volume
  - apnea
  - Cheyne-Stokes respirations
  - accessory muscle use
  - last reflex breaths

... Changes in respiration

- **Fears**
  - **suffocation**
- **Management**
  - **family support**
  - **breathlessness**

Loss of ability to swallow

- Loss of gag reflex
- Build-up of saliva, secretions
  - scopolamine to dry secretions
  - postural drainage
  - positioning
  - suctioning

Neurological dysfunction

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

Terminal delirium

- ‘The difficult road to death’
- Medical management
  - benzodiazepines
    - lorazepam
  - neuroleptics
    - haloperidol, chlorpromazine
- Seizures
- Family needs support, education

Communication with the unconscious patient ...

- Distressing to family
- Awareness > ability to respond
- Assume veteran can hear

... Communication with the unconscious patient

- Create familiar environment
- Include in conversations
  - assure of presence, safety
- Give permission to die
- Touch

Pain

- Fear of increased pain
- Assessment of the unconscious patient
  - persistent vs. fleeting expression
  - grimace or physiologic signs
  - incident vs. rest pain
  - distinction from terminal delirium

Loss of ability to close eyes

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

Loss of sphincter control

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

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

Signs that death has occurred

- Absence of heartbeat, respirations
- Pupils fixed
- Muscles, sphincters relax
- Release of stool, urine
- Eyes can remain open
- Jaw falls open

Moving the body

- Prepare the body
- Choice of funeral service providers
- Wrapping, moving the body
  - family presence
  - intolerance of closed body bags

Pronouncing death

- Entering the room
- Pronouncing
- Documenting

Telephone notification

- Sometimes necessary
- Use six steps of good communication

EPEC

The Education in Palliative and End-of-life Care program at Northwestern University Feinberg School of Medicine, created with the support of the American Medical Association and the Robert Wood Johnson Foundation

Module 14e

Spiritual Needs

Objectives

- **Be able to understand:**
  - **the purpose of spiritual care**
  - **the difference between spirituality and religion**
  - **three key roles of a chaplain**
  - **palliative care team roles**

Introduction

- Spiritual questions:
  - “What has my life been about? What will it be about now?”
  - “Where was God when I was wounded?” “Can I be forgiven for things that I did during combat?”

Spiritual concerns

- “What is happening to my body? Will I die?”
- “Do I believe in a higher being? Do I believe in God
- “How have I treated people and the world-at-large?”
- “Did I live true to my values? Did I live true to my beliefs?”

Definitions

- **Spirituality**

  a relationship between the individual and the greater world

- **Religion**

  an expression of this relationship by a particular group

Goals of spiritual care

- To address the sense of isolation that accompanies serious illness.
- To help patients and loved ones find their own internal sense of meaning and purpose, comfort, strength, and/or balance.

FICA

- Faith and belief
- Importance of faith and belief
- Community
- Address spiritual needs

Four core areas of spiritual well-being

- Hope
- Waiting for a miracle
- Dealing with change and uncertainty
- Fears about life and death

Spiritual assessment by the chaplain

- Psychological and spiritual struggles
- Lack of apparent connection to spirituality

The chaplain’s role

- Humane presence
- Tradition and community
- Reflection on spiritual concerns

The team’s role

- Listening
- Facilitating life review
- Helping attend to unfinished business

Sustaining personhood

- Talk to the ill patient, rather than about them
- Ask patients how they are doing or feeling
- Explore what it is that helps that patient feel like a human being
- Offer choices and help patients identify areas where they can have some control

Sustaining community

- Family
- Friends
- Community organization
- Faith community

Creating a spiritual legacy

- Ethical wills
  - example of questions
    - “What have you learned from life?”
    - “What values, wisdom, or life lessons would you like to pass on?”
    - “What would you want your loved ones to remember about you? About life? About themselves?”

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ANYTHING ELSE?