DID YOU JUST SAY THE “H” WORD?

PRESENTER BIOGRAPHY

Sara Dado, LCSW
Sara is a graduate of The University of Northern Iowa and The University of New York at Albany. She has been working in the field of healthcare for over 18 years and currently serves as Executive Director for Transitions Hospice. Sara is a passionate advocate for quality end of life care and advanced care planning. She enjoys providing education to community groups on the importance of advance directives and how to start the conversation on hospice care.
LEARNING OBJECTIVES

• Be aware of common misconceptions of hospice care and tips to overcome these barriers.
• Discuss obstacles to hospice admission, including how to normalize death.
• Analyze data on cultural, gender, age and spiritual variations relevant to acceptance of hospice care.
• Ethical concerns for the healthcare/hospice professionals who are asked to not mention the “H” word or advise patient of terminal prognosis.
• Implications for practice standards.
CASE STUDY #1 IN ETHICS

- Julie is a hospice patient in a home setting.
- She is alert and oriented but with periods of confusion and increased lethargy.
- Family has asked that staff not tell her she is on hospice, remove name badges and refrain from talking to her about the dying process.
- What do you do? How does this affect your ability to provide quality end of life care to this patient and family?

Obstacles and Objections

- I still have hope…
- We are/I am not ready!
- But she loves her home health nurse…
- I am not DYING
- My family does not want me to give up…
- My doctor told me I don’t need hospice…
- But I heard there is a clinical trial?
WHAT IS THE BIGGEST OBSTACLE WE HAVE TO OVERCOME IN HOSPICE CARE??

• Hospice means GIVING UP HOPE

WHAT IS HOPE?

• According to Merriam-Webster:
  • To want something to happen or be true and think that it could happen or be true
  • to cherish a desire with anticipation
HOW DO WE FIND HOPE:
In the face of….
DEATH?
FEAR?
LOSS OF CONTROL?
GRIEF?
SADNESS?
NEW BEGINNINGS?

PARADIGM SHIFT—FINDING HOPE IN DEATH

<table>
<thead>
<tr>
<th>Event</th>
<th>Hope</th>
</tr>
</thead>
<tbody>
<tr>
<td>New diagnosis</td>
<td>A cure</td>
</tr>
<tr>
<td>Treatments options, doctors, hospital stays</td>
<td>Improved health, more time, less pain</td>
</tr>
<tr>
<td>Stopping treatment, enrolling in hospice</td>
<td>Staying home, spending time with family</td>
</tr>
<tr>
<td>Declining health, acceptance of terminal condition</td>
<td>Comfortable, life review, enjoying family and friends.</td>
</tr>
<tr>
<td>A few days to hours before death</td>
<td>The sun might shine tomorrow. A good death</td>
</tr>
</tbody>
</table>

CHANGING THE FACE OF HOPE

• Patients with terminal illness don’t know what to hope for…
  – Denial vs. hope
  – Well trained hospice teams know how to help patients and families understand how to move along the continuum of hope:
    • Provide a safe place for conversation
    • Encourage open discussion regarding fears and regrets
    • Family acceptance is key- people NEED assurance to that their loved ones will be ok without them.

Hope for a cure  ➔  Hope for a good death

MYTHS AND MISCONCEPTIONS

• Hospice is where you go to die…
• I can’t afford it…
• I don’t want to leave my home…
• But I don’t have cancer…
• Hospice is for the elderly – I’m not old!
• Hospice will take away all my medications
• I can’t see my doctor anymore
• I won’t be able to go to the ER
• It means giving up….
• Hospice is not part of our culture/religion…. There may be a miracle….
SO WHAT’S GOING ON – WHY CAN’T THE PATIENT/FAMILY HEAR US?

- Conversations occur on 2 planes:
  - Factual vs. Emotional (Emotional always wins!)
    - We cannot process cognitive info when we are emotionally flooded.
    - When info is too painful, we resist acknowledging it (Denial).
    - Emotional reactions tell us what is most important or scary at this time.
    - We are making them confront or see something they do not like or want to face.

So what do we do? What can we say?

- Figure out what is happening- fear often drives emotions.
- Don’t give to much information in that moment – instead attend to the emotions of patient/family. Open the door for honest conversation.
- Acknowledge “This is scary” “This is overwhelming.”
- Do not fight over the facts, instead say: “This is not what we wanted to happen” “This is not the outcome we were hoping for”
- People will hear what they want to hear when they are emotionally flooded. Stop if needed and readdress later.
- Try to identify the emotions the family is expressing and see if you can acknowledge or name the situation for them.
OTHER FACTORS INFLUENCING ACCEPTANCE OF HOSPICE

- Ethnicity
- Age
- Gender
- Spiritual – Religious Beliefs
- Economic Status
- Family Composition

FACTS AND FIGURES

Percentage of hospice patients in 2014

- White: 76.0%
- African American: 7.6%
- Hispanic/Latino: 13.1%
- Asian: 3.1%
- American Indian: 0.3%

NHPCO, 2015
RACIAL BARRIERS IN HOSPICE CARE
AFRICAN AMERICAN CULTURE

• Studies show consistent underuse of hospice services despite population growth. Distrust of healthcare system cited in objections.
• Lack of diversity in hospice teams is an issue.
• African Americans consistently report lower satisfaction rates surrounding end of life care.
• African Americans are 50% more likely to receive intensive aggressive care in a hospital setting than white counterparts.
• 65% less likely to have completed an advance directive during the last 6 months of life.

Rhodes, 2006

RACIAL BARRIERS IN HOSPICE CARE
HISPANIC/LATINO CULTURE

• Fastest growing ethnic minority group in the US
• Most unlikely of any group to use hospice services for end of life care.
• Report the most misconceptions regarding what hospice care entails (orphanage=poor house)
• Family and spiritual beliefs regarding end of life care of high importance.
• Least likely to desire open conversation about death and dying

Taxis, Keller Cruz, Less
2008
Kreling 2010
RACIAL BARRIERS IN HOSPICE CARE
ASIAN AMERICAN CULTURE

- Least amount of research available for this group.
- Chinese Americans have reported difficulties in reconciling traditional cultural beliefs with expectations for advance care planning.
- Western ideal of “informed consent” can be a barrier in a culture that values family centered decision making.
- Hospice use varies greatly within subsections of the culture (i.e., Filipino Americans more likely to use hospice care than Chinese Americans).

Quyen, 2008

IMPLICATIONS FOR PRACTICE

- Culturally competent hospice care
  - Meeting families where they are:
    - Ongoing education regarding disease process and end of life expectations
    - Breaking down language barriers – using indirect means of talking about death – culturally respectful
  - Modifying our expectations
    - Family decision making vs. informed consent
    - Understanding the barriers
    - Every patient and family is unique
    - Avoid stereotypes
    - Encourage open and honest conversation

Kreling et al(2010)
### FACTS AND FIGURES

#### Gender Percentages of Hospice patients in 2014

<table>
<thead>
<tr>
<th>Gender</th>
<th>Percentages of Hospice patients in 2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>46.3</td>
</tr>
<tr>
<td>Women</td>
<td>53.7</td>
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NHPCO 2015

#### Age Percentage of Hospice patients in 2014

<table>
<thead>
<tr>
<th>Age</th>
<th>Percentage of Hospice patients in 2014</th>
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</thead>
<tbody>
<tr>
<td>Less than 24 years old</td>
<td>0.5%</td>
</tr>
<tr>
<td>25-34</td>
<td>0.3%</td>
</tr>
<tr>
<td>35-64</td>
<td>15.3%</td>
</tr>
<tr>
<td>65-74</td>
<td>16.8%</td>
</tr>
<tr>
<td>75-84</td>
<td>26%</td>
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<tr>
<td>85+</td>
<td>41.1%</td>
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NHPCO 2015
FACTS AND FIGURES

<table>
<thead>
<tr>
<th>Payer</th>
<th>Percentage of Use by hospice patients in 2014</th>
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<tbody>
<tr>
<td>Medicare Hospice Benefit</td>
<td>85.5%</td>
</tr>
<tr>
<td>Private Insurance/Managed Care</td>
<td>4.0%</td>
</tr>
<tr>
<td>Medicaid Hospice Benefit</td>
<td>5.0%</td>
</tr>
<tr>
<td>Charity Care/Uncompensated</td>
<td>0.7%</td>
</tr>
<tr>
<td>Self Pay</td>
<td>0.8%</td>
</tr>
<tr>
<td>Other Payment Source</td>
<td>1.2%</td>
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Low income urban residents lack of utilization due to: Insurance, access to providers, co-pays, lack of access to medical care

NHPCO 2015; Mahoney et al (2008)

GENDER, AGE AND ECONOMIC FACTORS IN HOSPICE ADMISSIONS

- Women use hospice care more than men
  - Why?
    - Women live longer and are more likely to want to discuss end of life care.
  - The “old, old” population (age 85+) most likely to use hospice services
  - Medicare most used payer for hospice care services (dx other than cancer)
  - Do “only” children resist hospice for their parents more than large families?
    - Harder to let go? Less support system? Guilt?

NHPCO, 2015
PRACTICE GOALS TO CONSIDER?

• How to increase the utilization of hospice care, regardless of gender, race, economics or age.
  – Consider the Conversation
  – Respecting all cultures and belief systems
  – Economic factors effect access to services

• Are young terminally ill people underutilizing hospice services?
  – Research is limited.

• Improve access to hospice care for undocumented, uninsured, economically challenged, and underserved populations.
  – NFP vs. FP hospice providers
    • All people deserve death with dignity

Hiruy, Mwanri (2014)

UTILIZE YOUR TEAM!

HOW INTERDISCIPLINARY TEAM CAN HELP WITH RESISTANCE TO HOSPICE CARE

• Informational Liaison
• Admit RN
• Chaplain
• Social Worker
• Volunteer
• Primary Care Physician
• Palliative Care MD
• Palliative Care APN
ETHICAL CONSIDERATIONS
WHEN FAMILY REQUESTS.....
CAN HOSPICE STAFF ETHICALLY WITHHOLD DISCUSSION THAT
THE PATIENT HAS BEEN SIGNED ON TO HOSPICE SERVICES OR
INFORMATION REGARDING PLAN OF CARE?

NO!
REGULATIONS SAY THAT:
* PATIENTS HAVE A RIGHT TO PARTICIPATE IN DECISIONS ABOUT
THEIR CARE
* SET THE COURSE OF THEIR TREATMENT
* REFUSE TREATMENT
TO MAKE INFORMED DECISION ABOUT TREATMENT, PATIENTS MUST
BE GIVEN FULL AND ACCURATE INFORMATION.
MORE RIGHTS:
TO KNOW DIAGNOSIS, PROGNOSIS, TREATMENT OPTIONS, RISKS AND
RIGHT TO DECLINE TREATMENT

HEALTHSTREAM REGULATORY COMPLIANCE CLINICAL I (2014); LEWIS (2013)

OTHER ETHICAL CONSIDERATIONS

• Is it ethical – even when there are no advanced directives – to subject an elderly patient to aggressive interventions?
• The financial gain of a medical system who continues to perform futile tests/procedures for profits?
• Barriers exhibited by primary care physicians/home health staff who are resistant to refer patients to hospice.
CASE STUDY #2

Raymond is a Hispanic immigrant living in a nursing home with dementia. His English is fairly good and he can be combative and hostile with staff.

- Family request staff not refer to themselves as hospice as this causes Ray to become agitated and anxious.
- During a visit, Ray asks the hospice social worker if he is dying?
- How do you respond?

WHAT DOES THE FUTURE HOLD FOR HOSPICE SERVICES?

- Name change to Supportive Services? Future Care?
- Implications for definition of hospice care – culturally accepted in society that fears death
- Specific ethical standards for nurses, social workers, chaplains
- Promote education on Palliative Care as medical specialty
- Payment changes are coming
- Concurrent care – PC along with HC
- Primary Care MDs feel threatened – how to overcome?
“As a well-spent day brings happy sleep, so a life well used brings happy death.”
- Leonardo da Vinci

“You matter because you are you, and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also live until you die.”

Dame Cicely Saunders – Social Worker and Founder of the Hospice Movement

Thank you for attending!

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REFERENCES


Healthstream Regulatory Compliance Clinical I (2014)

REFERENCES


