END OF LIFE DISCUSSIONS IN THE REHAB SETTING

21st Annual Spring Social Work Conference 2023

1

BRIEF PRESENTER BIO

Alicia Wilderman, MHSA, CMC, CBIS studied at the University of Evansville and completed her Masters and Bachelor's degrees in Health Services Administration with a Gerontology Certificate. Alicia is a Certified Care Manager and a Certified Brain Injury Specialist. For the past 11 years Alicia has worked as a Case Manager in the acute rehabilitation hospital setting Her additional past experience includes home health care, dementia care, skilled nursing facilities, and long term care. Alicia is passionate about aging and gerontology services, advanced directives, and brain injury rehabilitation.

alicia.wilderman@encompasshealth.com

2

LEARNING OBJECTIVES

* The role of advanced directives at end of life
* Practical tips for end of life (EOL) discussions

3

WHAT IS REHAB?

A journey with promise and hope for recovery

Per the World Health Organization (WHO) "A set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment."

Example Health Care settings include: acute rehabilitation hospitals, home health care, assisted living, and skilled nursing facilities

* Physical Therapy, Occupational Therapy, and Speech Therapy

4

TYPICAL EXPECTATIONS IN REHAB

* We expect the patient to get better!
* Achieving goals
* Promoting healing and strength
* Improvement
* Recuperation
* Being on the mend
* Rally

5

WHAT HAPPENS WHEN RECOVERY DOESN'T GO AS PLANNED?

Patients and families could be faced with an unexpected end of Life (EOL) journey.

6

SIGNS AND SYMPTOMS

What to look for when a patient is not progressing

7

SIGNS AND SYMPTOMS

- * Activity level decreases significantly
- * Interest in surroundings fade
- * Desire for food and drink ceases
- * Bowel and bladder changes
- * Vital sign changes
- * Lab work changes
- * Increased pain
- * Respiratory deterioration
- * Significant weight loss
- * Worsening wounds
- * Agitation or periods of restlessness
- * Change in skin coloring
- * Consciousness fades
- * Sensory changes – illusions, hallucinations, delusions, near death awareness
- *Overall clinical picture, a combination of multiple medical conditions*

I GOOGLED YOUR SYMPTOMS
YOU HAVE 1 WEEK TO LIVE

8

WHAT HAPPENS NEXT?

The driver of clinical information about the plan of care comes from the MD/DO/NP/PA overseeing the patient in conjuction with input from any applicable specialty physicians

Ultimately led by the MD/DO/NP/PA

9

WHO DO YOU HAVE THE EOL CONVERSATION WITH

The WHO is just as important as the HOW

* The patient is the most important team member

* Decision making capacity

* If the patient lacks capacity look for surrogate decision maker

* Who does the patient/POA also want involved in the conversation?

10

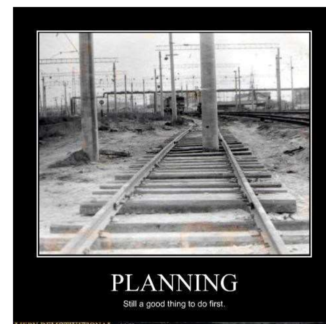
ROLE OF ADVANCED DIRECTIVES

* Varies by state
* Health Care Representative
* Medical Power of Attorney (POA)
* Out of Hospital DNR
* POST Form
* Living Will

11

PLANNING AN EOL CONVERSATION

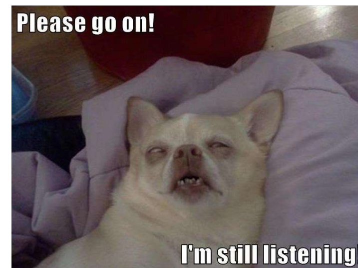
* Be well informed of the medical history, present situation, and family dynamics
* Special considerations with health literacy, education level, culture, and religious preferences
* Use the Who/What/When/Where/How Structure
  - Who? Should be present
  - What? Is the goal in mind
  - When? Time contraints
  - Where?
  - How?....................



12

MORE ABOUT *HOW*

* "Listen First" Approach – ask open-ended questions and hear their perspective and where they are coming from; this helps set the stage
* Use layman's terms as appropriate to set the tone
* Monitor your own energy, tone, and body language
* Empathy and compassion



13

FOUR STEP APPROACH

1. Initiate Discussion
2. Clarify Prognosis
3. Identify EOL Goals
4. Develop a Treatment Plan

14

WHEN IN DOUBT, START WITH DISCUSSING CODE STATUS

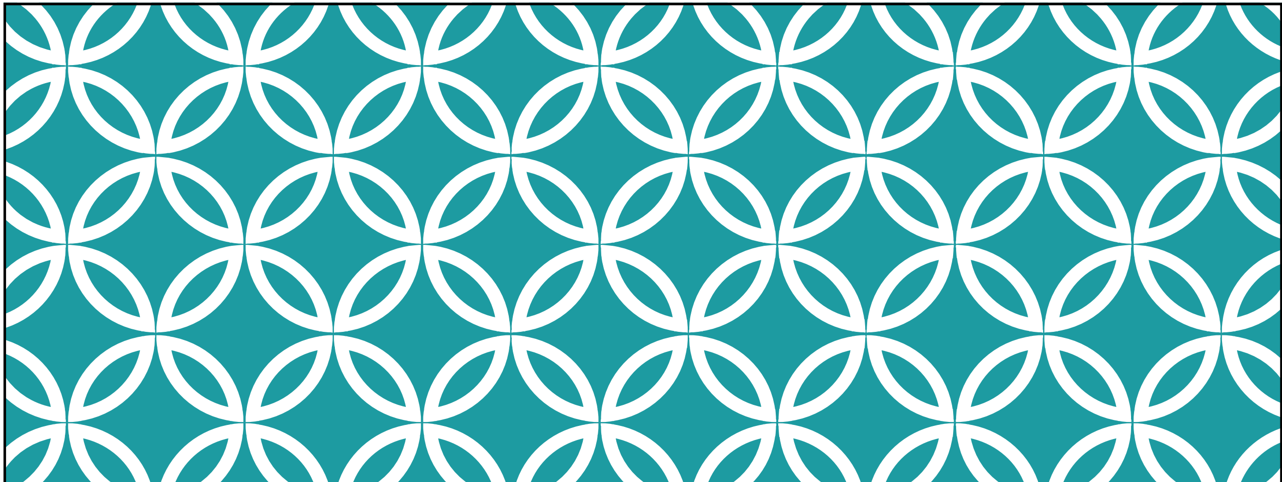
* Full code vs. DNR

* An appreciation of the limitations of CPR is necessary to make an informed decision regarding its use

* People often know about CPR from what they see on TV

* People are unaware of the poor outcomes of CPR for the chronically ill

15



SAMPLE CPR CONVERSATION DIALOGUE

16

SAMPLE CONVERSATION

With some patients we use cardiopulmonary resuscitation. This means that if your heart stops beating, we would try to use electric shock and chest compressions to get your heart beating again. If you stopped breathing, we would attempt to assist your breathing with a tube in the lungs. I know on television that these treatments usually work, but in real life, these treatments are rarely successful.

For someone in your condition, with widespread cancer, these treatments are almost never successful Most patients die in spite of resuscitation efforts, or may live for a few more hours or days before dying. The people who do survive resuscitation are generally people who are relatively healthy to begin with.

We have talked about your illness and your poor prognosis. You have told me about how you want to spend your final months. I also need to know your thoughts about using cardiopulmonary resuscitation.

17

ADDITIONAL TIPS AND CONSIDERATIONS

* Avoid post-conversations – hallway conversations – known as “splitting”

* Importance of summarizing the conversation at the end

* Religious / spiritual involvement in the discussion

* Culturally appropriate

* Listen, communication, compassion

* The need for additional follow up conversations

* Financial limitations and obligations

* Role of denial

* Listen to the patient’s actions and symptoms – What are they trying to tell us when they are refusing to eat, refusing to get out of bed, etc.

18

DEVELOPING A PLAN OF CARE

Palliative Care vs. Hospice Care

Palliative care for ANY patient with a chronic illness who is experiencing a decreased quality of life because of symptoms related to their illness or treatment, like renal dialysis, oxygen therapy, or chemotherapy. Hospice care is a type of palliative care for patients who are no longer receiving curative treatments for their illnesses, and want to focus ONLY on quality of life.

Hospice patients have a prognosis of six months or less, if the illness were to follow the usual course. Palliative care is the umbrella, where we are focusing on symptom control to get you through treatments, advanced care planning, and quality of life. Hospice and end-of-life care fall under the umbrella when the focus of care changes. Bereavement care is also under that umbrella, for family support after a death.

19

"PALLIATIVE REHABILITATION"

Cheville et al. has defined *palliative rehabilitation as function directed care delivered in partnership with other disciplines and aligned with the values of patients who have serious and often incurable illnesses in contexts marked by intense and dynamic symptoms, psychological stress, and medical morbidity to realize potentially time-limited goal (Manfredi et al., 2000).*

* *Palliative care and rehabilitation align in their philosophical approaches to patients, particularly in their commitment to improve overall* Quality of Life (QofL) and commitment to interdisciplinary treatment approaches

* *Common ground*

20

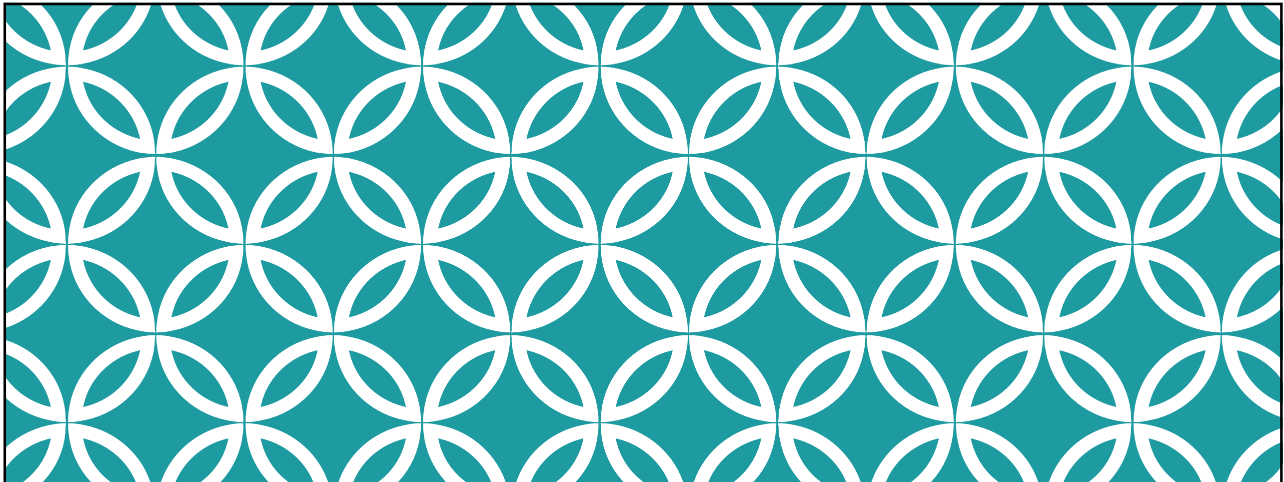
EOL DISCUSSIONS

* With EOL discussions some clinicians are "naturals" yet for others it is a skill that can be learned

* Talking about EOL is a skill we can improve

* Practice, practice, practice

21



CASE STUDIES

Scenarios for Practice

22

CASE STUDY SCENARIO 1

Mr. Z is a 76 year old male admitted to the acute rehabilitation hospital for a primary diagnosis of right hip fracture status post total hip replacement. His comorbidities include HTN, DM II, GERD, and Osteoarthritis. Mr. Z is retired and lives with his 67 year old wife who works part-time. This is his second marriage and they have been married for seven years. He has two sons that live out of state. He is a full code with no advanced directives. Prior to coming to the acute rehabilitation hospital he had encephalopathy and confusion post surgery. On day three of his acute rehabilitation hospital stay he had a severe basal ganglia stroke. The attending physician chose to do all diagnostic testing and treatment in-house at the acute rehabilitation hospital and not have the patient return to the acute care hospital. Two weeks have gone by and Mr. Z continues to deteriorate. He is alert and oriented to self only, has not eaten in two days, is refusing medications, and has difficulty swallowing. The attending physician has done all possible intervention, Mr. Z is not improving, and the physician is recommending EOL discussion.

23

CASE STUDY SCENARIO 2

Mrs. A is a 96 year old who lives alone in a two story home with five steps to enter with no handrails. Three daughters live nearby and check in on their mom about two or three times a week to visit. Mrs. A is at the acute rehabilitation hospital for gangrene to the left foot and is non weight bearing on her left lower extremity after having two toes amputated. She is on continuous IV Antibiotics for six weeks for an infection in her foot. Family claims Mrs. A was fully independent prior to this hospitalization but the interdisciplinary team suspects Mrs. A showed signs and symptoms of memory loss or potential dementia over the past several months and the three daughters were in denial of this. The three daughters express rehab goals that the patient must be fully independent with all mobility, ADLS, IADLS, and medication management for her to return home alone. The daughters express they are not willing to increase their visits or family support nor consider having their mom stay with one of the daughters upon discharge. In previous discharge planning conversations between the three daughters, Mrs. A, and the Case Manager, there has been previously zero discussion between Mrs. A and her daughters of what the plan would be once Mrs. A could no longer live alone independently. There has never been any discussion regarding considerations for future long term care planning needs, who could help, financial planning, etc. Mrs. A has a poor response to the IV Antibiotics. Mrs. A shows worsening cognition and cannot remember her non weight bearing status. Mrs. A goes into respiratory distress. She is now on a non-rebreather with six liters of oxygen. She is a full code with no advanced directives, and Mrs. A and her daughters have never previously discussed her EOL wishes. The attending physician anticipates poor prognosis and requests an EOL conversation.

24

IN CONCLUSION

* Death taboo

* Death adverse society

* Emotional demands and time involvement with these conversations

* Repetition and practice improves your ability with these types of discussions

* EOL conversations are the most challenging of all communication scenarios in health care

25

MORTALITY RATE IS STILL 100%

26

RESOURCES

Indianapost.org/patients/#additionalresources – this is a 12 minute video

Honoring Choices Indiana www.honoringchoicesindiana.org

National Hospice and Palliative Care Organization www.caringinfo.org

PREPARE www.prepareforyourcare.org

Information on POST: www.polst.org

27

REFERENCES

"Which Critical Communication Skills Are Essential for Interdisciplinary End-of-Life Discussions? Mark Pfeifer, MD and Barbara A. Head, PhD, CHPN, ACSW, AMA Journal of Ethics, August 2018, Volume 20, Number 8: E724-731

"The Intersection of Rehabilitation and Palliative Care: Patients With Advanced Cancer in the Inpatient Rehabilitation Setting" Lynne S. Padgett, PhD, Arash Asher, MD and Andrea Cheville, MD, Rehab Nursing Journal, www.rehabnursingjournal.com, July/August 2018, Volume 43, Number 4

"A Physicians Guide to Talking About End-of-Life Care" Richard B. Balaban, MD, Journal of General Internal Medicine, 2000; 15:195-200

"Palliative care? But I am not dying!" Karen Mulvihill DNP, APRN, ACHPN, FNP, ACHPB, https://www.wolterskluwer.com/en/expert-insights/palliative-care-but-i-am-not-dying, October 21, 2014

"Signs of Approaching Death" Hospice Foundation of America https://hospicefoundation.org/Hospice-Care/Signs-of-Approaching-Death

28