

# Improving the Quality of End of Life Care for Older Adults in Health Centers

Session 2

2018 Learning Collaborative Series

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# National Center for Equitable Care for Elders (NCECE)

[www.ece.hsdm.harvard.edu](http://www.ece.hsdm.harvard.edu)

**Who We Are-** Established in 2017, the National Center for Equitable Care for Elders (NCECE) is a training and technical assistance Center that provides innovative and culturally competent models of care, inter-professional training and educational resources to health care professionals providing care to older adults

**Our Mission** is to build strong, innovative and competent health care models by partnering with CHCs, PCAs and FQHCs to provide quality, and inclusive care for older adults



# Contact Information

Program Email - [ece@hsdm.harvard.edu](mailto:ece@hsdm.harvard.edu)

Program Manager - [Jini\\_Etolue@hsdm.harvard.edu](mailto:Jini_Etolue@hsdm.harvard.edu)

Program Director - [Christine\\_Riedy@hsdm.harvard.edu](mailto:Christine_Riedy@hsdm.harvard.edu)



# Health Center Resources Clearinghouse

- This comprehensive website provides easy access to a broad framework of resources, tools, and information developed by the National Cooperative Agreement (NCA) organizations, and additional partners soon! Check it out at [www.healthcenterinfo.org](http://www.healthcenterinfo.org).



# Session Leader



**Denise Snow JD, RN, CNM, NP**

Clinical Associate Professor in the School of Nursing, Stony Brook University



# EQUITABLE CARE FOR ELDERS

END OF LIFE DECISIONS- talking with your patients

Denise Snow, JD, RN, CNM, NP

# Objectives

- Discuss assessment strategies for identifying end of life care goals for health center patients
- Discuss how health centers can document end of life care including medical decision-making and life-sustaining treatment options.
- Discuss how to engage case managers and or social service staff in end of life care discussions.

# Diagnosis is just the beginning

- Patients face many social, financial and legal problems during the course of their treatment
- Clinicians must have an understanding of these issues, or communication will be ineffective
- An understanding of these issues will assure appropriate referral/intervention
- Coordinated care at the health center will insure that the patient's wishes for end of life are followed.

## When critical conversations about prognosis are avoided...

Next step planning/  
shoring up of resources... only addressed when treatment  
failure is obvious or crisis  
hospitalization

Social/legal problems  
become exigent especially  
in the dying patient:  
possibly now too ill to  
participate

Legal issues  
become the  
purview of  
hospitals and  
insurance  
companies

Complicated probate, extended hospitalization,  
burdensome financial legal legacies for families

This is something I have never heard a patient say to me

“My goal is to end my life in the intensive care unit of my local hospital”

So, why do approximately 1 in 5 people die in the ICU ?

Health centers are key to improving quality of life and incidentally, reducing health care costs (25% of all health costs are spent in the last year of life)

# So how should you prepare for end of life discussions?

## Some basics

1. Always knock, introduce, reintroduce yourself sit down before initiating a discussion with a patient in a clinical setting
2. Assess patient understanding of medical condition
3. Acknowledge the emotional subtext and respond to it.
4. Protect the patient's privacy and confidentiality when in an uncontrolled environment
5. Assess patient non-medical needs by exploring their social framework (see Medical-Legal Checkup)
6. Ask permission to create a plan based on the patient's values and needs.
7. Incorporate a summary of visit (wrap up) and follow-up. Document the discussion.

# Talking with the patient

**Your patient asks:**

*“What happens next”?*

*“I want to be prepared.”*

**How would you respond?**

# Responses

- *“I will take care of everything, you do not have to worry”*
- *Have your wife give me a call and I will tell her what we spoke*
- *“Yes, being prepared will help you and your family”.*

*Let's talk about some of your concerns.*

# Medical-Legal Checkup

- Is patient insured? Is it adequate?
- Does patient have a health care proxy? Does patient have someone to act on their behalf ( a Power of Attorney) if they are incapacitated \*
- If the patient does not have anyone to act as their health care/medical power of attorney, do they have a living will.
- What is the status of patient's housing? In danger of losing home?
- Does the patient have medical or consumer debt? Are they being pursued by creditors? Are they being sued or is there a judgment against them?
- Does the patient want or need a will? Have they updated beneficiary status on all investments, life insurance, bank accounts, annuities, retirement accounts, etc?
- Will the patient need long term care or home care? If so, who will help them apply?

*\*Critical to think about these issues immediately while client is competent. On occasion, it becomes too late to execute these important documents!*

# SELF DETERMINATION

- Every adult with decisional capacity has the right to consent to or refuse medical treatment even if that decision will result in the patient's death.
- The right to refuse treatment is a liberty interest protected by the due process clauses of the New York State and U.S. Constitutions

# The Patient Self-Determination Act

- The Patient Self-Determination Act (PSDA) is a federal law, and compliance is mandatory. It is the purpose of this act to ensure that a patient's right to self-determination in health care decisions be communicated and protected. Through advance directives--the living will and the durable power of attorney--the right to accept or reject medical or surgical treatment is available to adults while competent, so that in the event that such adults become incompetent to make decisions, they would more easily continue to control decisions affecting their health care.

# PRESUMPTION OF CAPACITY

- Every adult is presumed to have capacity to make medical decisions unless there has been a prior court determination or a court appointed guardian is authorized to decide about health care for the adult.

# COMPETENCE AND CAPACITY

- “Competence” and “Capacity” (short for “decision-making capacity”) are often used interchangeably.
- Competence is a legal term. Competence is presumed unless a court has determined that an individual is incompetent. A judicial declaration of incompetence may be global, or it may be limited (e.g., to financial matters, personal care, or medical decisions).
- Decision-making capacity, on the other hand, is a clinical term that is task-specific. A physician may determine that a patient does not have the capacity to make a decision for or against surgery, but may have the capacity to decide if she wants pain meds.

# Capacity Changes

- Capacity is defined (NY) as the ability to (1) understand and appreciate the nature of proposed health care, including the benefits of, and alternatives to, proposed health care; and (2) reach an informed decision.
- The determination of capacity does not mean that the person is free from all mental impairment.
- In order to make valid treatment decisions, a person must be able to (a) recognize there is a decision to be made, (b) understand the needed information, c) understand the treatment options, (d) understand the likely consequences of each option (i.e. risks, burdens, and benefits), and (e) rationally manipulate the information to come up with a decision consistent with his or her values.

# Communicating End of Life Care

DNR/ DNI- Perceptions of CPR are often at odds with reality

- When would they want to go to the hospital?
- When should the family call 911?
- How can they be sure their wishes will be followed?

Advance Directives

- Health Care Proxy/Medical Power of Attorney should be readily available- picture in phone, purse, glove compartment
- Involve the medical agent- do they know what the principles wants?

# Documenting the Patient's Wishes

Molst/Polst/Post/ Most forms:

- Initiate
- Update

A copy should be given to the family and directions on use the forms and a copy should go in the patient's medical record.

Time should be set aside to review the forms every 6 months or as the patient's condition changes

Know how rapid responders/EMS treat these forms in your community

## And Lastly....

- The seriously ill patient may need extensive assistance in the home. Documentation from your health center will make the difference between a patient getting that assistance, or struggling without it.
- Remember- administrative forms may seem repetitive and time consuming, but completing them on time is essential for the patient with a serious illness.

## Thanks!