# Serious Illness Conversation:

## Guidance for Caregivers

1

**Carolyn Harrison, MN**
**Nurse Educator**

**Presentation for HOT TOPICS**
**August 25, 2022**
**WSU Metroplex**

2

3

## Objectives

1. Discuss two approaches to conversation with those facing life threatening situations.

2. Identify three open-ended questions you can ask regarding goals of care in mortal time.

3. Understand the importance of a TPOPP (Transportable Physician Orders for Patient Preferences) form to document patient wishes for care." Approaches to serious illness conversation

4

## Have you had a conversation with a person who has or had a chronic, advanced illness or terminal illness?

- Think back to the situation and experience.
- Who started the conversation about their illness?
- Were you uncomfortable?
- Were you afraid to ask questions?....about the person's diagnosis, plans for care, fears or concerns?

5

## Case: What would you do?

- You receive a call from a family member or good friend.
- She/He says, "I think I have terminal cancer."
- What would you say?

6

**Serious Illness Conversations for us calls for:**

- Courage
- Empathy
- Sensitivity
- Honesty
- Sympathy
- Nonverbal communication

7

**Communication about serious illness care goals: a review and synthesis of best practices.**

Bernack, RE and Block, SD. JAMA Intern Med. 2014 Dec. 174(12): 1994-2003

**Conversations with patients about their care goals helps clinicians to align the care provided with what is most important to the patient.**

8

**Content of Serious Illness Care Conversation documentation is associated with goals of care orders.—a quantitative evaluation in hospital**

**King, S. et al. BMCPalliat Care 2022 Jun 29; 21(1):116**

- Study was to help establish whether delivery of prognostic information, encouragement of Adv. Directives and discussion of terminal treatment options can meaningfully alter the last portion of a patient's life.
- 175 patients in a tertiary hospital, medical teaching unit uses "goals of care designation" medical orders
- CONCLUSION: "SICP increases quality of documentation about patients' values and priorities."

9

**Pitfalls in communication that lead to nonbenficial emergency surgery in elderly patients with serious illness: description of the problem and elements of a solution** Cooper., Z et al. Ann.Surg. 2014 Dec 260(6):949-57.

- Surgeon, patient surrogate and systemic factors including time constraints,
- inadequate provider communication skills and training,
- uncertainty about prognosis,
- patient and surrogate anxiety and
- limitation in advance care planning contribute to communication challenges
- "Communicaton breakdowns may lead to nonbeneficial procedures in acute events near the end of life."

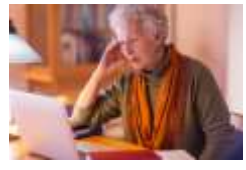
10

What serious illnesses might you see in your practice in caring for adults or children with chronic, advanced or terminal illness?

11

**CASE STUDY**

- Sue had back pain for a year
- Went to FP physician
- Referred for MRI
- Given diagnosis of pancreatic cancer
- Referred to oncologist

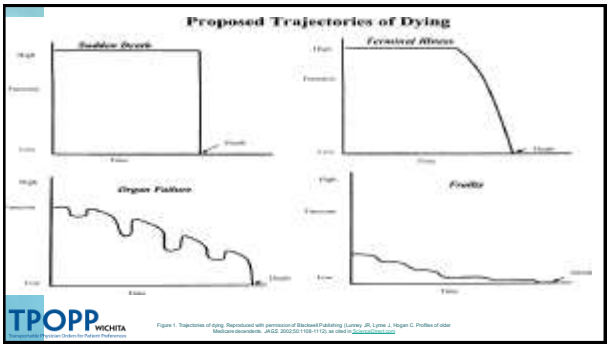


12

## Patients experience different types of Illness trajectories of illness and dying

TPOPP WICHITA
Transportable Physician Orders for Patient Preferences

13




TPOPP WICHITA
Transportable Physician Orders for Patient Preferences

Figure 1. Trajectories of dying. Reproduced with permission of Blackwell Publishing (Lunney JR, Lynn J, Hogan C. Profiles of older Medicare decedents. JAGS 2002;50:1108-1112), as cited in ScienceDirect.com

14

## Definition of "Mortal Time"

McQuellon, R.P. and Cowan, M.A. The Art of Conversation Through Serious Illness

- "Mortal time is 'Kairos time'...the ancient Greek word meaning "the time of decisions." pg. 15
- "...is a reminder of that challenging, difficult truth, which each of us faces, more or less consciously, throughout life." pg.7
- "Mortal time is entered when death comes near." pg.14

15

## Ask the "surprise question"

- **Would you be surprised if this person died in the next year?**
- **If the answer is "NO," then it is time for a serious illness conversation.**

16

**First Approach: The Serious Illness Conversation Guide**
https://www.ariadnelabs.org/serious-illness-care

- Framework for physicians, nurses, social workers, chaplains, allied health professionals, and other clinicians
- Explores topics that are crucial to gaining a full understanding about and what is most important to patients with chronic, advanced or terminal illnesses.
- More, better and earlier conversations with the clinicians about goals, values and priorities for future care.

17

## Second Approach: Caring Conversations Consider what your agent needs to know

Center for Practical Bioethics-Caring Conversations

- **What is your diagnosis (disease or illness)?**
- **What is your expected prognosis (course of illness)?**
- **Considering your diagnosis and prognosis, what is the best case or worse case that you may experience?**
- **What are your healthcare providers' treatment goals?**

18

**Second Approach: CARING CONVERSATIONS**
Center for Practical Bioethics.org

- **What are the treatment options? How will they affect my prognosis?**
- **How will treatment options affect my well being and my day-to-day life?**
- **What do you (healthcare provider) recommend be done next?**
- **If I decide to do nothing – what will happen next?**

19

**THE CHALLENGE**

When we face serious illness, with our patients and those we love, there are tough conversations to have that can be frightening, difficult, and confusing.

20

**THE CHALLENGE**

- ***Only one third of patients*** **in their last year of life report having these serious illness conversation.**
- **These conversations *take place too late in the illness* course to help fulfill the patient's most important wishes.**
- **Clinicians agree that these conversations matter, but *seventy-one percent don't have a system to routinely ask patients about their goals.***
  - AriadneLabs.org/SeriousIllnessConversationGuide

21

## SERIOUS ILLNESS CONVERSATION GUIDE

- (SEE HANDOUT given at today's HOT TOPICS presentation
- Go to google.com/ariadnelabsseriousillnessconversationguide.

22

## THE BENEFITS OF CONVERSATION

- **Persons who have conversations with their caregivers about their goals, values and wishes for care are more likely to**
  - **receive the care they want.**
  - **feel less distress.**
  - **and report better quality of life.**
    - **www.Ariadnelabs.org/serious=illness=care**

23

## STRATEGIES

- **Takes change in the system**
- **Need useful tools and guides for conversations**
- **Routine clinical practice**
- **All specialties and care settings need to be involved.***
  - **www.ariadnelabs.org/wp-content/uploads/2021/06/noun_Project_3185882.png>**

24

## The serious illness conversation ties in with TPOPP –Transportable Physician Orders for Patient Preferences

TPOPP FORM documents the conversation's goals of care for the patient.

25

**Center for Practical Bioethics**
**Kansas City, Missouri**

## Brought TPOPP to Kansas & Missouri

TPOPP WICHITA
Transportable Physician Orders for Patient Preferences

26

## What is TPOPP?

- Transportable Physician Orders for Patient Preferences
- Modeled on the Physician Orders for Life Sustaining Treatment (**POLST**) paradigm
- One of the efforts underway nationally to address conversations about end of life care. POLST started in Oregon and Washington over 20 years ago.

TPOPP WICHITA

27

## Who Might Have a TPOPP Form?

- **Those who**:
  - -- Live with advanced progressive chronic illness
  - -- May expect death to occur within the next year
  - -- Wish to further define their care wishes
- ***TPOPP is NOT appropriate for:***
  - -- A person with stable medical condition or disabling problem with years of life expectancy
  - -- Anyone who does not want it

*TPOPP is a voluntary decision*

TPOPP WICHITA
Transportable Physician Orders for Patient Preferences

28

## What is TPOPP WICHITA ?

Transportable Physician Orders for Patient Preferences

- A community conversation initiative sponsored by TPOPP Partners: Ascension Via Christi Health, HCA-Wesley Medical Center and the Medical Society of Sedgwick County

- Includes a form to document conversations had with patients to confirm their GOALS OF CARE.
- See www.TPOPPWichita.com
- www.practicalbioethics.org

TPOPP WICHITA
Transportable Physician Orders for Patient Preferences

29

## What do people want/not want at the end of life/ "mortal time?"

We need to know -- to plan for their care.

30

Traj

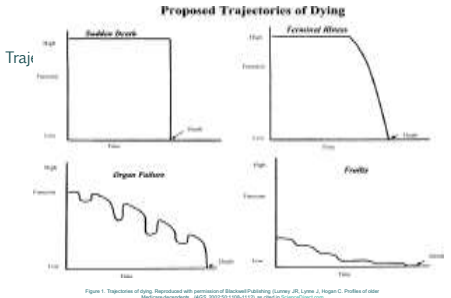



Figure 1. Trajectories of dying. Reproduced with permission of Blackwell Publishing (Lunney JR, Lynn J, Hogan C. Profiles of older Medicare decedents. JAGS. 2002;50:1108-1112) as cited in ScienceDirect.com

TPOPP WICHITA
Transportable Physician Orders for Patient Preferences

31

## Chronic illness trajectory

**•Patients need to know the trajectory of their illness (what is ahead) and make a plan for the next "crisis" or anticipate what they want done at end of life.**

-- Requires the system and the physician to recognize the illness trend and discuss with the patient goals of care

-- Requires planning from the hospital, the primary care physician, and the nursing home

-- Requires the coordinated effort of the support systems so the patient's preferences are known across the continuum of care

32

*When we are successful with serious illness conversations and TPOPP*

- We will make a major improvement in matching the care we provide to the care our patients desire
- We will impact how and where patients and their families experience end-of-life
- We will improve the level of coordination across the care continuum for one of the most vulnerable populations while respecting their voice

TPOPP WICHITA
Transportable Physician Orders for Patient Preferences

33

## Suggestions for What Should Be Done

- Increase training for Serious Illness Conversation
- Use SIC Guide and Caring Conversations online
- Provide yourself permission to approach family members, friends, patients with conversation about their "goals of care" if they have a chronic, advanced illness or terminal illness.



34

## Suggestions for What Should Be Done

- Create and give support to family, friends, and healthcare professionals to have more conversations.
- Use TPOPP form to document conversations.
- Order TPOPP forms from Center for Practical Bioethics.Org or Medical Soc. Of Sedg. County
- It will take a societal change. It is happening!

35

## BIBLIOGRAPHY


- Online sources:
  - Ariadne Labs. A Joint Center for Health Systems Innovation (www.ariadnelabs.org and Dana-Farber Cancer Institute.) Revised April 2017.
  - www.practicalbioethics.org Caring Conversations workbook
  - tpopp@practicalbioethics.org
  - TPOPPWichita.com


36

## BIBLIOGRAPHY

- Film
- Books
  - Gawande, Atul. BEING MORTAL: Medicine and What Matters in the End. Metropolitan Books, Henry Holt and Company. New York. 2014
  - McQuellon, R.P. and Cowan, M.A. THE ART OF CONVERSATION THROUGH SERIOUS ILLNESS. Oxford University Press.2010.

37

## BIBLIOGRAPHY

Slide # 30.
Figure 1. Trajectories of dying. Reproduced with permission of Blackwell Publishing (Lunney JR, Lynne J, Hogan C. Profiles of older Medicare decendents. *JAGS*. 2002;50:1108-1112). as cited in ScienceDirect.com



38

## QUESTIONS???



39