“Goals of Care,” A Buzz Phrase Needing Clarity

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Case Example

- The palliative care consult team receives a page from the HUC for request for “goals of care” for a patient on the hospitalist team
- Consultant reviews the chart:
  - Patient: malignant bowel obstruction and functional decline in the context of widely metastatic colorectal cancer
  - Not a surgical candidate
  - Discussions documented by hospitalist team on global health picture, prognosis, and desire for information on next steps
- Attempt made to reach hospitalist team, covering provider unable to provide further information
- Consultant completes consult without direct conversation with referring provider

Case Example

- Patient interaction
  - Consultant elicits patient understanding
  - Patient conveys wish to avoid physical suffering and future hospitalizations
  - Consultant assumes no further systemic cancer treatment options to be offered
  - Hospice is recommended for post-hospitalization care
- Consultant/primary team interaction
  - Concerns shared about hospice discussion
    - naïve to systemic cancer treatments
    - hospice recommendation felt premature and confusing
  - Clarifies “goals of care” to mean code status and escalation of care preferences

“Since you are the experts in communication,

I thought you could do this better than me”

Objectives

- Analyze this case which illustrates the pitfalls of “goals of care” as a buzz phrase
- Review the literature and approaches among various specialties and patient populations for establishing “goals of care”
- Propose a unified definition
- Discuss standardized process for establishing them for all patient populations

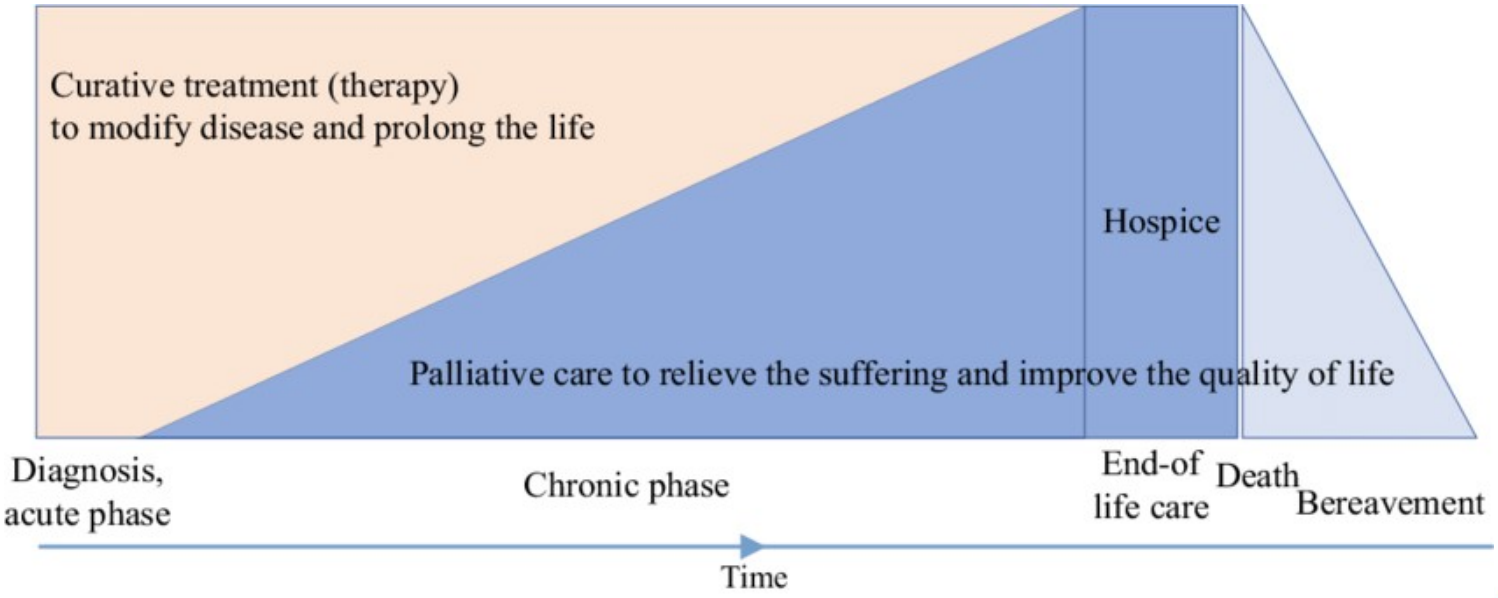
Consult requests

- “GOC: to decrease length of stay”
- “GOC: patient is not happy with current nursing home…provide more dispo options”
- “GOC: patient has been in the hospital for 3 months”
- “GOC: patient still full code”
- “GOC: life-prolonging care is not working”

The Evolution of Palliative Care as a Specialty

- 1990, the WHO recognizes Palliative Care as a specialty
- Considered “terminal care,” separate from and mutually exclusive with treatments that cure the underlying disease or treat the underlying pathophysiology
  - Sharp transition from disease-oriented therapy to palliative care
- Hospice historically developed as a Medicare benefit
  - Requires patients to “give up” treatment for their underlying disease
- Negative perception of all else has failed gets reinforced

The Evolution of Palliative Care as a Specialty



Primary, Secondary, and Tertiary Palliative Care

- Hospice and Palliative Medicine: similar to other specialties in consultation scope
- Primary vs secondary vs tertiary care
- Great deal of variability in the services to which **patients** have access
  - Variability in physicians' practice patterns, awareness, and training

Consultation services

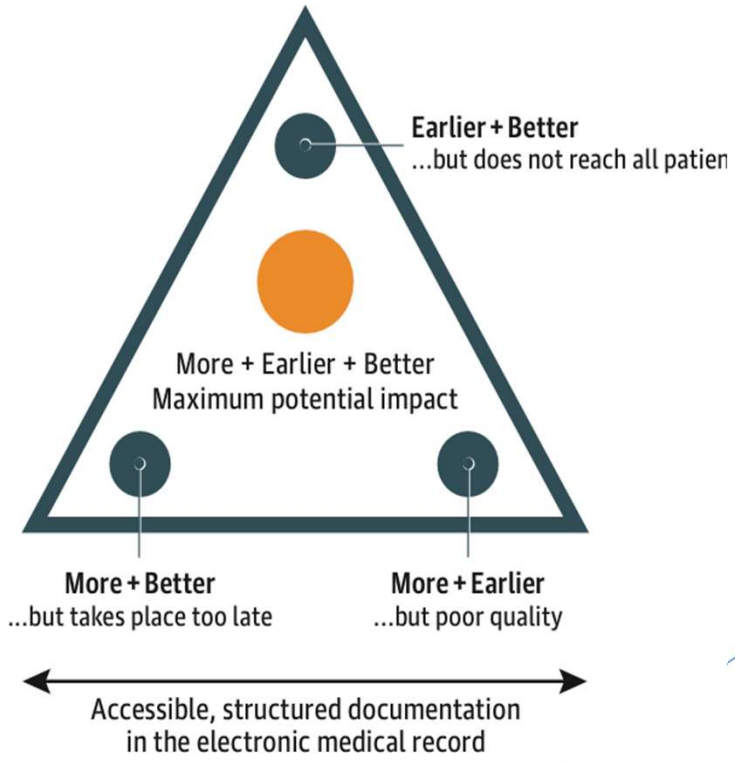
- Most prevalent model of palliative care service delivery in acute care hospitals
  - Despite guidelines for best practices, also notable **variability in palliative care service delivery** exist
- There is an urgent need to improve basic palliative care assessment and treatment skills among clinicians caring for seriously ill patients
  - Systems-change approach

Rationale for standardized approach

- Shared-decision making in acute situations is difficult
  - Patient/Surrogate- anxiety, readiness
  - Provider – training, ambiguous responsibility, time constraints
  - System- inadequate support in eliciting and documenting patient goals
- Prognostic Uncertainty
- Provider and patient goals may differ
  - Cognitive and emotional dissonance
- Increasingly fragmented healthcare system dependent on the EMR
  - Majority of discussions take place in acute care, 1 month before death, and are often inadequate, inconsistent, or inaccessible.

Establishing Goals of Care

- Associated with…
  - Better QOL
  - Reduced utilization of non-beneficial medical care near death
  - Enhanced goal-consistent care
  - Reduced costs
  - Positive family outcomes
- Patients with serious illness often feel their doctors do not provide all info about illness and options
  - How to understand treatment goals?



Brief Literature Review; constructs we are currently using for leading GOC discussions

- Proposed Communication Framework in surgery
- Communication/GOC in the Oncology literature
- Nursing home communication framework
- REMAP
- GOC Concept Clarification

Communication Framework in Surgical Emergencies

- Structured approach
  - 9 key elements
    - Formulate prognosis
    - Create personal connection
    - Disclose information regarding the acute problem in the context of the underlying illness
    - Establish shared understanding of patient condition
    - Allow silence and deal with emotion
    - Describe surgical and palliative treatment options
    - Elicit patient's goals and priorities
    - Make a treatment recommendation
    - Affirm ongoing support for patient and family

Communication Framework in Surgical Emergencies

- Need to identify/recognize conditions that put patients at risk for nonbeneficial treatments
  - Permanent nursing home resident
  - Cancer- worsening performance status, no more disease-modifying treatment
  - Heart failure
  - Long term oxygen therapy
  - ESLD
  - ESRD
  - Worsening neurological disease
  - Complete functional dependence
  - Aspiration

Communication Framework in Surgical Emergencies

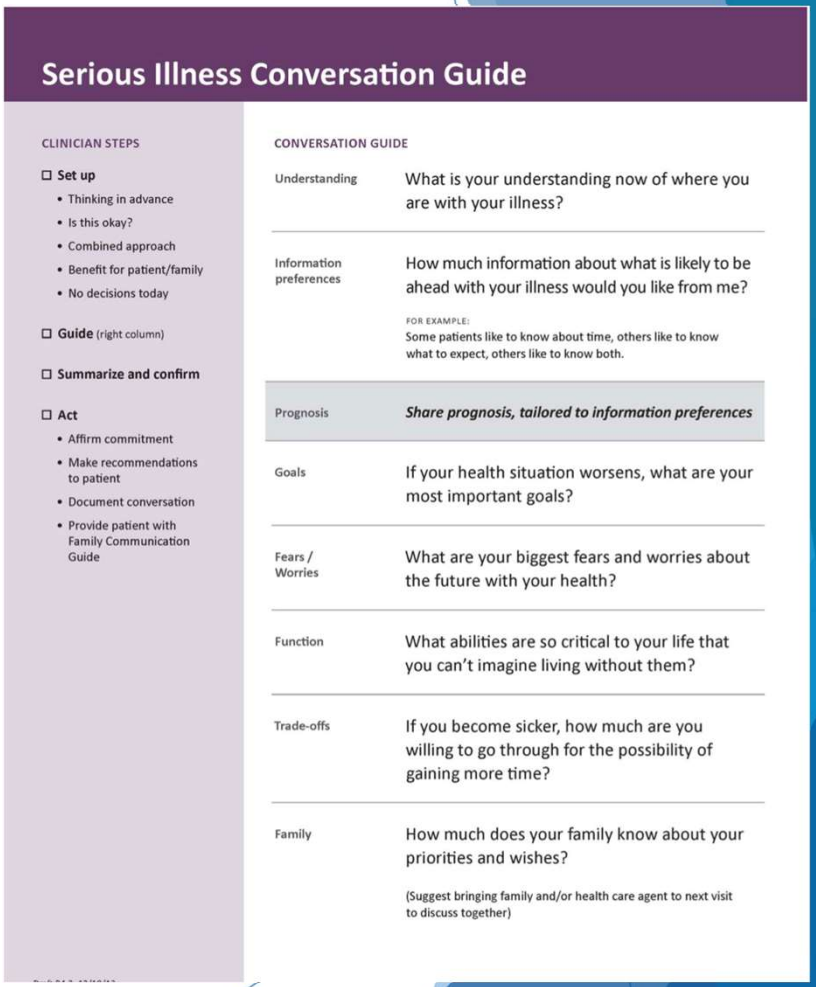
- Barriers to shared decision making
  - Patient/surrogate
  - Surgeon
  - **System**
    - Fragmented sources of information
    - Time constraints
    - Lack of upstream convos
    - Default assumptions
    - Lack of evidence for long-term outcomes

TABLE 2. Barriers to Shared Decision Making and Communication in Surgical Emergencies

Patient and surrogate
Understanding of chronic illness
Acuity of illness/severity of symptoms
Patient lacks decisional capacity
Surrogate preparedness for their role
Lack of established Patient-Provider relationship
Patient's decisional capacity/style
Health literacy/expectations
Current quality of life
Emotions
Advance care planning
Prior medical experience
Surgeon
Prognostic uncertainty
Surgical buy-in
Lack of training in communicating with seriously ill patients
Ethical construct of "do everything"
Personal values about end-of-life care
Inexperience or discomfort comfort with palliative care
System
Fragmented sources of information
Time constraints
Lack of upstream end of life conversations
Limited availability of palliative care
Local practice patterns
Default assumes desire for surgery and ICU care
Clinical inexperience of on-call surgeons
Lack of evidence on long-term mortality, functional outcome and quality of life, and end-of-life care in older adults after emergent surgery

Oncology Literature

- Plethora of communication tools and tips
- RCT of palliative care communication intervention
- Serious Illness Care Program
  - Tested, scalable, specific to certain population
- Primary outcomes: receipt of goal-concordant care and peacefulness at EOL



Serious Illness Conversation Guide

CLINICIAN STEPS

☐ **Set up**
- Thinking in advance
- Is this okay?
- Combined approach
- Benefit for patient/family
- No decisions today

☐ **Guide** (right column)

☐ **Summarize and confirm**

☐ **Act**
- Affirm commitment
- Make recommendations to patient
- Document conversation
- Provide patient with Family Communication Guide

CONVERSATION GUIDE

Understanding	What is your understanding now of where you are with your illness?
Information preferences	How much information about what is likely to be ahead with your illness would you like from me? FOR EXAMPLE: Some patients like to know about time, others like to know what to expect, others like to know both.
Prognosis	***Share prognosis, tailored to information preferences***
Goals	If your health situation worsens, what are your most important goals?
Fears / Worries	What are your biggest fears and worries about the future with your health?
Function	What abilities are so critical to your life that you can't imagine living without them?
Trade-offs	If you become sicker, how much are you willing to go through for the possibility of gaining more time?
Family	How much does your family know about your priorities and wishes? (Suggest bringing family and/or health care agent to next visit to discuss together)

Oncology Literature

- Results from Serious Illness Conversation Guide RCT
  - Clinician experience
    - Enabled them to evaluate prognostic understanding
      - Titrate to patient needs and preferences
    - 90% agreed that SICG allowed discussion in a timely manner w/simple format
  - Patient experience
    - 35% reported increased peacefulness, hopefulness about QoL and life expectancy
    - 56% reported increased closeness with their clinician
    - 46% reported increased sense of control over medical decisions

Oncology Literature

- Improvement in:
  - Documentation of at least 1 serious illness conversation before death
  - Timing of the initial conversation before death
  - Quality of conversations
  - Their accessibility in the EMR
- Significant reductions in anxiety and depression at 14 weeks

REMAP

- Stepwise process to help clinicians with goals of care conversations
  - Reframe
    - Provide a headline
  - Expect emotion
  - Map out patient values
  - Align with values
  - Propose a plan

Table 2. Strategies for Mapping Values

Strategy	Example
Asking about advance directives	"Have you ever completed a living will?"
Asking about values directly	"What's most important to you now, with what you know about your illness?" "What else?"
Reflecting on emotion	"You feel sad thinking about the possibility that you won't see your children grow up. It sounds like time with your children is one of the most important things for you now."
Exploring worries	"As you think about the future, what concerns you?" "What do you want to avoid?"
Exploring life outside the hospital or clinic	"What kind of things do you like to do when you're feeling stronger?"
Personal experience with medical interventions	"What has chemotherapy been like for you?"
Family/friend experience with medical interventions	"Has anyone close to you been in the intensive care unit or on a breathing tube? What was that like?"
Exploring recent quality of life	"How has your life been for the past year since you've had more health problems?"

Operationalizing “goals of care” Nursing Home Examples

- Defining the onset of dying is a persistent challenge
- Disagreements about appropriateness of care or ambiguous health status
- Lack of consistency in understanding or interpreting GOC
- Medicare hospice benefit operationalizes dying as the 6 months prior to death

Other proposed definitions

Table 1. Potential goals of care

- Cure of disease
- Avoidance of premature death
- Maintenance or improvement of function
- Prolongation of life
- Relief of suffering
- Optimized quality of life
- Maintenance of control
- A good death
- Support for families and loved ones

Concept clarifications to date

"**Thoughtful interaction** between a human being seeking medical care and the healthcare team."

- Implicit goal is usually cure or survival = "default"
  - Assumed before thoughtful interaction
- GOC associated with end-of-life care and quality of life, or palliative care
  - Implicit to explicit occurs when treatment is no longer achieving desired goals
  - **Difficult d/t assumption that GOC occurs because a patient is "at end-of-life"**
- Goals change throughout the disease trajectory

Operational Definition

"Establishment of agreed on, desired health expectations that are **appropriate**, **documented**, and **communicated**."

Goal-concordant care

- Definition:
  - Clinical care that helps reach a patient-identified goal, and respects any treatment limitations that patient has placed on clinical care
- Patient goals are individualized and distinct from therapeutic goals (cure, life prolongation, or palliation)
- Challenges
  - No standardized location to document patient goals
  - Decision-making capacity limitations
  - Biases upon data collection (recall, social desirability)

Can we measure this?

- Challenges
  - How to establish a baseline measure of patient's goals against which to assess the concordance of future care is difficult
  - Goals may change between ascertainment and time care is evaluated
  - How to determine whether patients' experiences of the care they receive aligned with their original goals is fraught with bias
- Valuable outcome measures in trials of serious-illness interventions
- Predefined categories, knowledge/training required for correct classification, need EHR-predictive algorithms with high fidelity

Back to the case

- Analysis
  - Numerous breakdowns in communication
    - No direct communication between referring team and consulting team
    - Pace of inpatient care and complexity of care teams involved led to substandard inter-team communication
  - Lack of clear understanding of the phrase “goals of care”
- Lack of shared expectations
  - Code status needs to be readdressed
  - Employing life prolongation as fundamental goal of medical interventions needs to be reconsidered

Goals of care = patient is not doing well clinically

Proposal for a Unified Definition

Table 1. The First Step: Ascertain Whether There Is a Shared Understanding of the Primary Aim of Medical Treatment

Cure disease
Prolong life through control of disease and/or rehabilitation
Maximize comfort-oriented care

Proposal for a Unified Definition

- Merge commonly-referenced definitions, guides, and algorithms into a clinically applicable 2 step process and standardize it throughout health systems.

Table 2. The Second Step: Elicit Patient-Centered Goals of Medical Interventions

Goal	Example
Functional	Improve or maintain current functional status or mobility
Survival	Avoid premature death, maximize dignity, and/or quality of life
Family	Attend an event, leave a legacy, avoid burden on family
Mentation	Maintain cognitive status or maximize alertness
Psychosocial	Make peace with family/faith, complete a will

Practical Application

- Primary team assesses patient's understanding of primary intent of medical interventions by using step 1
  - Would a formal "goals of care" or serious illness discussion be needed to negotiate consensus?
  - Facilitates cogent clinical recommendations within the framework of an overarching goal of medical care
- Expectation matching
- Translation into the EMR
- Primary palliative care -> standardized language and documentation

Managing Conflicts through this Process

- Some Examples
  - When patients' expectations differ from provider expectations
  - Patient is declining, but goals are still life-prolongating
  - Prognostic awareness discussion performed, and patient still wants to be full code
- We need a practical framework for open, truthful, realistic, and contextual communication between providers and patients

Goal concordant care: revisited

The patient's understanding of the primary aim of medical treatment aligned with what clinicians felt was medically possible (step 1) and his/her individualized goal of medical treatment (step 2) was ultimately achieved.

Discussion

- How would you have approached this consult differently?
  - As the primary team?
  - As the consultant?
- What are your triggers for calling a goals of care consultation?
- What do you tell the consulting team when you receive a consult for GOC?

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Thank you