Tips for Tackling Conflicting Goals of Care in Seriously Ill Patients: What to do when the Goals of Care get Stuck!

Lindy Landzaat DO, FAAHPM
Assistant Professor
Hospice & Palliative Medicine Fellowship Director
@lindylandzaat

Karin Porter-Williamson MD, FAAHPM
Associate Professor
Division Director of Palliative Medicine
Objectives

• By the end of the session participants will be able to identify goals of care conflicts in the seriously ill patient population and list potential reasons and strategies to address conflicts.
A little review
Palliative Care tries to meet the needs of...

Patient  Family  Team
Most Palliative Care Consultations:

- Introduce Self/Team
- Assess Understanding: “Tell me what you understand about your condition”
  - Poor Understanding
  - Average Understanding
  - Great Understanding
  - Assessing Values & Goals of Care: “Knowing what you know, what things are most important to you at this stage?”
  - Work to fill in gaps first
### What do “Goals of Care” mean?

<table>
<thead>
<tr>
<th>Patient/Family</th>
<th>Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do you <strong>HOPE</strong> that the treatment will achieve?</td>
<td>What are we <strong>DOING</strong>? What is the focus of the medical plan?</td>
</tr>
</tbody>
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*The University of Kansas Health System*
What do “Goals of Care” mean?

**Patient/Family**

- Hope

**Team**

- Doing
  - Cure
  - Better function
  - Reaching a milestone
  - Comfort
  - Help others
  - Save/rescue
  - Optimize function
  - Extend life
  - Manage symptoms
Patients’ Goals of Care Categorized

- Structured literature review of 116 articles
- Most commonly articulated GOC
- Categorized into 6 domains

<table>
<thead>
<tr>
<th>Goal of Care</th>
<th>Number of Citations</th>
<th>Percentage of Citations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Be cured</td>
<td>72</td>
<td>62.1</td>
</tr>
<tr>
<td>2. Live longer</td>
<td>89</td>
<td>76.7</td>
</tr>
<tr>
<td>3. Improve or maintain function/quality of life/independence</td>
<td>87</td>
<td>75.0</td>
</tr>
<tr>
<td>4. Be comfortable</td>
<td>113</td>
<td>97.4</td>
</tr>
<tr>
<td>5. Achieve life goals</td>
<td>62</td>
<td>53.4</td>
</tr>
<tr>
<td>6. Provide support for family/caregiver</td>
<td>46</td>
<td>39.7</td>
</tr>
</tbody>
</table>

Kaldjian, Am J Hospice & Pall Med
When Dealing with Goals of Care

Photo credit: Jeff Kubia “Slot Machine”
Goals of Care

Patient

Family

Team
Goals of Care
Optimally, all line up!!

With a Solvent Plan!
Goals of care MUST drive the plan of care!
Components of informed goals of care

- Willingness to communicate
- Provider ability to relay medical info/ prognosis
- Pt/family ability to develop prognostic awareness
- Pt/family ability to reflect on values & preferences
- Pt/provider ability to coalesce the information into aligned goals & patient-centered plan of care
In Essence:
Shared Decision Making
Goals mismatch = stuck plan

• Can happen between any pairing in the triad of patient, family, and team (system)

• Different potential drivers for each of these types of mismatch...
Goals of Care

Patient  Family  Team
Pt goals different from family/team: a differential diagnosis

• Low prognostic awareness
  Not aware of the prognosis
Provider Prognostic Communication

- Takes Time, Skill, Courage
- Repeated studies indicate that physicians do not engage in discussions of prognosis with their patients
- MGH 2014 study looking at associations between patient prognostic awareness and their treatment goals as well as their quality of life and anxiety in GI cancer patients
  - 50 patients
  - 78% pancreatic cancer, vs other GI
  - 0 receiving chemo for curative intent!!
  - Had had a mean of 8 oncology visits at time of study

El-Jawahri. Cancer 2014
In this study, only 22% reported any goals/prognostic discussion with oncologist. Patients with a more accurate understanding of illness also had more realistic treatment goals. Patients with more prognostic awareness had worse QOL and anxiety scores. Authors: don’t avoid prognostic conversations; more support needed as patients come to terms with their prognosis.

Prognostic Awareness

El-Jawahri. Cancer 2014
Pt goals different from family/team: a differential diagnosis

• Low prognostic awareness
  Not aware of the prognosis

• Denial (a survival mechanism)
  ‘This information is too painful to accept’
Pt goals different from family/team: a differential diagnosis

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  ‘This information is too painful to accept’
- Value priorities demand a different goal
  ‘Something else is more important’
Taxonomy of patient values impacting shared decision making.

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Pt goals different from family/team: a differential diagnosis

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- Lack of trust in what providers are saying
  ‘I’ve heard it before, and it didn’t come true’
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- Lack of access to trusted provider
  ‘I need to hear this info from the doctor that knows me’
Lack of access to trusted provider

1. Are they available to visit?
   - Joint visit
   - Before/after clinic

2. Can they call patient?
   - Cell
   - Room phone

3. Coordinate?
   - I’ve spoken to Dr. Smith, here’s what he told me…

4. Wait for the follow up appt?
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• Mutual protection
  I’m protecting you, you’re protecting me, by not talking
Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment

Alexi A. Wright, MD
Baohui Zhang, MS
Alaka Ray, MD
Jennifer W. Mack, MD, MPH
Elizabeth Trice, MD, PhD
Tracy Balboni, MD, MPH
Susan L. Mitchell, MD
Vicki A. Jackson, MD, MPH
Susan D. Block, MD
Paul K. Maciejewski, PhD
Holly G. Prigerson, PhD

Context  Talking about death can be difficult. Without evidence that end-of-life discussions improve patient outcomes, physicians must balance their desire to honor patient autonomy against a concern of inflicting psychological harm.

Objective  To determine whether end-of-life discussions with physicians are associated with fewer aggressive interventions.

Design, Setting, and Participants  A US multisite, prospective, longitudinal cohort study of patients with advanced cancer and their informal caregivers (n=332 dyads), September 2002-February 2008. Patients were followed up from enrollment to death, a median of 4.4 months later. Bereaved caregivers’ psychiatric illness and quality of life was assessed a median of 6.5 months later.

Main Outcome Measures  Aggressive medical care (eg, ventilation, resuscitation) and hospice in the final week of life. Secondary outcomes included patients’ mental health and caregivers’ bereavement adjustment.

Results  One hundred twenty-three of 332 (37.0%) patients reported having end-of-life discussions before baseline. Such discussions were not associated with higher rates of major depressive disorder (8.3% vs 5.8%; adjusted odds ratio [OR], 1.33; 95% confidence interval [CI], 0.54-3.32), or more worry (mean McGill score, 6.5 vs 7.0; P=.19). After propensity-score weighted adjustment, end-of-life discussions were associated with lower rates of ventilation (1.6% vs 11.0%; adjusted OR, 0.26; 95% CI, 0.08-0.83), resuscitation (0.8% vs 6.7%; adjusted OR, 0.16; 95% CI, 0.03-0.80), ICU admission (4.1% vs 12.4%; adjusted OR, 0.35; 95% CI, 0.14-0.90), and earlier hospice enrollment (65.6% vs 44.5%; adjusted OR, 1.65; 95% CI, 1.04-2.63). In adjusted analyses, more aggressive medical care was associated with worse patient quality of life (6.4 vs 4.6; F=3.61, P=.01) and higher risk of major depressive disorder in bereaved caregivers (adjusted OR, 3.37; 95% CI, 1.12-10.13), whereas longer hospice stays were associated with better patient quality of life (mean score, 5.6 vs 6.9; F=3.70, P=.01). Better patient quality of life was associated with better caregiver qual-
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Goals of Care

Patient  Family  Team
Family goals different from pt/team: a differential diagnosis

- Low prognostic awareness
  Family not aware of the prognosis
Clinician perceived Barriers to goals Discussions

Figure 1. Importance of Barriers to Goals of Care Discussions as Perceived by Clinicians on Medical Teaching Units

- Family members’ difficulty accepting one’s poor prognosis
- Family members’ difficulty understanding limitations/complications of life-sustaining therapies
- Lack of agreement amongst family members about goals of care
- Patients’ difficulty understanding limitations/complications of life-sustaining therapies
- Patient lacks capacity to make goals of care decisions
- Patient difficulty accepting poor prognosis
- Language barriers
- Lack of availability of substitute decision maker(s)
- Cultural differences
- Uncertainty about who is the substitute decision maker
- Uncertainty in estimating prognosis
- Lack of time
- Unaware of what other team members have said
- Health care team disagreement about goals of care
- Lack of preexisting relationship with patient/family
- Lack of training to have these conversations
- Patient does not have advance directive
- Advance directive lacks sufficient detail
- Lack of appropriate location (confidential/private)
- Desire to maintain hope
- Desire to avoid being sued

Symbols and error bars denote the point estimates and 95% CIs of the mean importance score for a given barrier. Questionnaire items were rated on a scale from 1 to 7, with 1 indicating “extremely unimportant” and 7 indicating “extremely important.”

You J. et al.; JAMA Internal Medicine April 2015
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  Family not aware of the prognosis
- The seagull
  Here comes the out-of-town cavalry
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  I don’t know who I’ll be without them
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  If I discuss it, then they will think I’m giving up on them
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  ‘I’ve heard it before, and it didn’t come true’

• Values/beliefs
  If I discuss it, then they will think I’m giving up on them

• Secondary gain
  ‘If mom dies, where will the kids and I live?’
Goals of Care
Team goals different from pt/family: a differential diagnosis

- Providers want to provide treatments
  ‘But I can still help’
  ‘Don’t want to steal hope’
Conceptual Models of Hope

A. Alternate existence of hope and information “back-forth” diagram
B. Balance of hope information “scales” diagram
C. Harmonious integration of hope and information “yin-yang” diagram
D. Redirection of hope “redirect” diagram

Curtis 2008
Wish/Worry statements

- Words matter
- Avoid linking statements with “but”, it negates whatever you said first.
- “I wish that David will get strong enough for chemo too. I worry that may not be the case. Is that something you’ve allowed yourself to consider as well?”
Team goals different from pt/family: a differential diagnosis

• Providers want to provide treatments
  ‘But I can still help’
  ‘Don’t want to steal hope’

• Providers don’t want to give non-beneficial Rx
  ‘It feels like we’re only prolonging suffering’
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  - ‘It feels like we’re only prolonging suffering’
- Provider goals = a questionable long-shot
  - ‘If you can do XYZ then maybe we can get you to ABC’
Team goals different from pt/family: a differential diagnosis

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- Provider goals = a questionable long-shot
  - ‘If you can do XYZ then maybe we can get you to ABC’
- System pressures
  - ‘I want to avoid the patient bouncing-back’
Recurrent admissions: tensions?

- Patient sees it as tune ups
- Who is this working for?
- Who is this NOT working for?
- Why?
Suggestions:

• Gotta do some honest, self-reflection
• Gotta recognize the emotion that accompanies
• “Name it”
• To expect a different outcome, something has to be different:
  – Stops working for the patient
    • Motivation change?
    • More support for home?
    • New alternative available?
  – Services no longer available
  – Circumstances change (pt becomes more ill)
    • Advanced Care Planning
  – Acceptance
**Situation**

- Driver making excessive frequent pit stops
- Who cares more about winning the race?
- If ‘the pit crew,’ consider:
  - Driver motivation?
  - Driver depression?
  - Crew expectations?

**Alternative Outcome**

- Driver changes technique; doesn’t need as many pit stops
  - Took crew members’ tips
- Driver opts for new pit crew
- Cost of pit stop gets too high: (financial, time, exhaustion)
- Pit Crew tosses in the towel
- Pit crew ‘Does it’s thing’
  - The race won’t last forever
Everyone aligned but the wheels keep spinning

Not a Solvent Plan!
Care Plans

• Goals can lead sometimes to a plan that cannot be delivered due to lack of access to resource, lack of payer, lack of provider systems knowledge

• All plans must be made in the context of their delivery
  – Plan should be solvent outside hospital
  – Identify Barriers
  – Draw on social work and case management early

• Patient ‘I still insist on this plan’…
  – Capacitated patients are allowed to make bad decisions
    • Time-limited trial
    • Deploy best safety nets
    • Develop a Plan B
    • Prep surrogates
Take Home Points

• Assess understanding, values, and patients’ priorities for their care to inform the medical plan.

• Don’t expect realistic goals of care if patient doesn’t have realistic understanding of condition & prognosis

• Any misalignment of goals along the triad of patient, family, provider, can stall the ability to create a solvent patient-centered plan

• When the goals are stuck, consider who’s not aligned & a differential diagnosis

• The Goals of care MUST drive the Plan of care!!!!
References

- You J. et al.; Barriers to Goals of Care discussions with seriously ill hospitalized patients and their families: A multicenter survey of clinicians. JAMA Internal Medicine April 2015 Volume 175, Number 4
- James Loesch, Photo: “Merry Go Pano”. https://www.flickr.com/photos/jal33. Available by Creative commons license CC BY 2.0
<table>
<thead>
<tr>
<th></th>
<th><strong>Palliative Care</strong></th>
<th><strong>Hospice</strong></th>
</tr>
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<tbody>
<tr>
<td><strong>When</strong></td>
<td>Anywhere in illness trajectory</td>
<td>Prognosis &lt; 6 MONTHS</td>
</tr>
<tr>
<td><strong>Where</strong></td>
<td>Usually in hospital, some outpatient programs</td>
<td>Goes to patient (Hospice is not a place)</td>
</tr>
<tr>
<td><strong>Goals of Care</strong></td>
<td>Variable</td>
<td>Comfort Directed Usually avoiding hospitalization</td>
</tr>
<tr>
<td><strong>Availability</strong></td>
<td>Depends on individual program</td>
<td>Planned visits 24/7 on-call</td>
</tr>
<tr>
<td><strong>Team Members</strong></td>
<td>Depends on individual program</td>
<td>Nurses, physicians, volunteers, chaplains, social workers, bereavement coordinators</td>
</tr>
<tr>
<td><strong>Levels of Care</strong></td>
<td>Primary Secondary Tertiary</td>
<td>Routine Continuous Care General Inpatient Respite</td>
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</tbody>
</table>
• Home health model
• Home bound
• Usually offered by a Hospice Company
• Incorporates some Hospice philosophy
• Can help make transition to hospice when ready