When the Goals of Care Get Stuck

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Objectives

• Understand the Concept of “Goals of Care”
• Understand concept of “values assessment” in shaping goals
• Explore the etiology of “mismatch”, when the goals of care don’t translate smoothly to a plan
• Explore strategies to align patient, family, and team stakeholders around a common set of goals and plan
• Understand importance of plan solvency, even when goals align well

What do “Goals of Care” mean?

• Patient/family: what is hoped treatment will achieve
  – Hope to achieve cure
  – Hope to achieve a level of function
  – Hope to be able to reach a milestone
  – Hope to assure comfort
  – Etc

• System/Provider: “What are we DOING? What is the focus of the plan”
  – Save/rescue
  – Optimize function
  – Assure comfort
Optimal: Goals of Care All matched up!!

Optimal: Patient, family, team goals/expectations all align and a solvent plan that everybody is happy with can be put into place.

What kinds of Goals do patients have?

- 7 Domains of Goals - Kaldjian et al.
  - structured literature review of 116 articles to identify and recommend the most commonly articulated goals of care

<table>
<thead>
<tr>
<th>Goal of Care</th>
<th>Number of Articles</th>
<th>Percentage of Articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintain status of health</td>
<td>87</td>
<td>75.4%</td>
</tr>
<tr>
<td>Live longer</td>
<td>57</td>
<td>49.7%</td>
</tr>
<tr>
<td>Improve symptoms or any other condition</td>
<td>46</td>
<td>39.4%</td>
</tr>
<tr>
<td>Be comfortable</td>
<td>111</td>
<td>97.4%</td>
</tr>
<tr>
<td>Achieve life goals</td>
<td>107</td>
<td>92.0%</td>
</tr>
<tr>
<td>Avoid levels of care</td>
<td>88</td>
<td>75.9%</td>
</tr>
<tr>
<td>Avoid terminal illness</td>
<td>94</td>
<td>80.2%</td>
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<tr>
<td>Avoid intentional deaths</td>
<td>77</td>
<td>65.9%</td>
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<tr>
<td>Avoid undergoing pharmacologic treatment</td>
<td>102</td>
<td>87.4%</td>
</tr>
<tr>
<td>Avoid hospitalization</td>
<td>102</td>
<td>87.4%</td>
</tr>
<tr>
<td>Avoid health care</td>
<td>102</td>
<td>87.4%</td>
</tr>
</tbody>
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What is needed to have well informed goals of care?

- Willingness to communicate
  - 47% of US adults state that clinicians consider their goals and concerns
- Provider ability to communicate medical information, especially about prognosis clearly, honestly, timely.
- Patient/family ability to develop prognostic awareness of medical situation
- Patient/family ability to reflect on values and preferences
- Patient/Provider ability to coalesce the information into a goal aligned, patient centered plan of care
In Essence: Shared Decision Making

Collaboration of provider giving information about best available evidence for treatment options, alongside patient consideration of values and preferences.

Provider Communication

• Takes Time, Skill, Courage
• Repeated studies indicate that physicians do not engage in discussions of prognosis with their patients
  • Temel et al. in Cancer, 2014
    - Study looking at associations between patient prognostic awareness and their treatment goals as well as their quality of life and anxiety
    - 50 patients, 78% of whom had pancreatic cancer and had had a mean of 8 oncology visits at time of study

Temel: desire to know prognosis, perception of ability to be cured

[Diagram showing patient preferences for knowing their prognosis and their desire to be cured]
**Temel: Preferences for information, goals**

- Patient preferences for death after cancer diagnosis and treatment
- Patient primary treatment goal

**Temel Study- Stand outs**

- Only 22% reported any goals or prognostic discussion with the oncologist
- The patients who had a more accurate understanding of illness also had more realistic treatment goals
- The patients who had more prognostic awareness had worse QOL and anxiety scores

**Patient/family willingness or ability to develop prognostic awareness**
Values Assessment

• Values: the unique concerns and preferences that each patient brings to a clinical situation

  • Digging deeper- what are values?
    – Global Values
    – Decisional Values
    – External Values
    – Situational Values

Fig. 2. Taxonomy of patient values impacting shared decision making.
Global Values

- Relevant to every decision regardless of scenario, lens through which all decisions are made
  - Value traits—tied to personality/temperament
    - Examples: risk averse, anxious
  - Life Priorities—what is most important in someone’s living
    - Commitment to parenting, commitment to a cultural norm, commitment to a spiritual belief
    - Hierarchy of priority—Independence above all else, mental clarity above all else, etc

Decisional Values

- Relate directly to the decision being made
  - Efficacy of treatment
  - Toxicity of treatment
  - Cost
  - Convenience
  - Impact on quality of life, length of life
- The medical evidence helps people weigh these variables
- The variables may compete with one another though

Situational and External Values

- **Situational Values**—reflect something specific and maybe temporary about the patient, environment, etc.
  - Patient who places high priority on physical comfort but wants to set this aside in favor of mental clarity in preparation for a loved one to visit

- **External Values**—patient consideration of others’ values in their decisions
  - Patient may have more comfort directed goals but continue to pursue more active treatment as that is what their child is hoping for
Decision Aids

- Tools to
  - Help patients imagine experiencing the physical, psychological, and social effects of different treatment options
  - Consider which positive and negative features of the choice matter most
  - Written material, video, computer module, independent or proctored by a provider

- Systematic review of Decision Aids at EOL
  - Magnolia-Cardona Morrell et al.
  - 17 studies met criteria
  - Treatment options/associated harms and benefits and patient preferences most commonly included.
  - Patient values, treatment goals, numeric disease-specific prognostic information and financial implications of decisions generally not.
  - DAs at the end of life are generally acceptable by users, and appear to increase knowledge and reduce decisional conflict.
  - The gaps in current decision aids may make them more appropriate for proctored completion.

Goals mismatch = plan can get stuck

- 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 not aligned with family and team
Patient goals different from family/team: differential diagnosis

- Low prognostic awareness
- Denial as a survival mechanism
- Value priorities demand a different goal
- Lack of trust in what providers are saying
- Lack of access to trusted provider

Goals of Care: family not aligned with patient and team

- The guilty Seagull
- The enmeshed partner
- Low prognostic awareness
- Lack of trust in medical providers
- Beliefs
- Secondary gain (kids live at moms house on her SS check, if she dies they all become homeless)
Goals of Care: patient and family not aligned with team

- Providers might have different goals than the patient/family
  - Providers want to continue to provide treatments that pt/family no longer want
  - Providers do not believe that ongoing treatments will work/will only prolong suffering
    - Prognostic awareness again important here
- Provider goals that may not be achievable
  - “If you get stronger you can get more chemo”
  - If you stop drinking, survive 6 months and get insurance, we can evaluate for transplant- (to an undocumented patient with a MELD of 40)

Strategies to Improve Alignment

- Pay close attention to the patient and family values assessment
  - Understand what is driving a particular goal
  - Understand the emotion behind the goal
  - Understand impact of spiritual/cultural beliefs
- Assess barriers to prognostic awareness
- Understand the locus of control
  - Attempt to reconcile what is and is not under our control
  - Wish, Worry, Wonder statements to create common ground and build trust
- Build parallel plans: a “Hope for the best plan”, and a “Safety net Plan” for in case things aren’t going as we hope
Everyone is aligned but the wheels keep on spinning and never stop

Patient  Family  Team

• Even if goals are aligned there has to be a solvent plan or it was all for naught

Creating Solvent Plans

• Patient/family/team goals can lead sometimes to a plan that cannot be delivered due to lack of access to resource, lack of payer
• All plans must be made in the context of their delivery
  – Plan must be solvent at home, not just at the big medical center
  • Inotropes and VAD management in frontier Kansas
  • Trach/Vent/Hemodialysis/Medicaid combo who does not want to move to Illinois
  • Lack of medication access or provider outside of urban area
    – Actiq/Subsys as an example

Goals of care MUST drive plan of care

• Cannot have mish mash of goals and plan
  – Want comfort measures only but then want code blue when decompensation happens
  – Want TPN but no lab draws

• A plan for testing/treatment created without the clear goal in mind can lead the patient/team down a dead end road that might not have been worth starting on
• “Interventions need to be situated in a framework of agreed upon goals” in order to make sense.
Take Home Points

• Good shared decision making should align well informed patient goals and values with a solvent treatment plan

• Outlining for patients how to think through what common goals are, and how to think more deeply about assessment of their values may inform discussion of goals meaningfully

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

• 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. JAMA Internal Medicine April 2015 Volume 175, Number 4