Goals-of-care Discussions for Seriously Ill Hospitalized Patients

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KEYWORDS

• Goals of care • Hospitalized patients • Medical decision-making • Treatment plan

HOSPITAL MEDICINE CLINICS CHECKLIST

1. Goals of care are individualized life goals that pertain to the health and well-being of patients.
2. Realistic goals of care usually emerge from a shared partnership between clinicians and patients.
3. An understanding of the patient's personal goals and values is critical for determining the direction of discussions.
4. A common theme among hospitalized patients with serious or potentially life-threatening illness is a focus on improving/maintaining quality of life and a tailored approach to disease management.
5. To identify treatment options that are realistic, patients must first have a good understanding of their diagnosis and prognosis.
6. A basic framework for goals-of-care discussions includes:
   a. Setting the stage
   b. Developing a common understanding of goals and priorities
   c. Making a recommendation that adapts medical options to that common understanding
   d. Summarizing and setting a follow-up meeting
7. Flexibility in timing the discussion is important for establishing a bond and avoiding conflict or inefficiency.
8. Basic communication skills such as Ask-Tell-Ask and Tell Me More allow clinicians and patients to better understand each other, foster collaboration, and minimize conflict.
9. Be aware of the emotional response of both patients and clinicians.
10. Be aware of unintentional meanings within the language you choose.
11. When conflict arises, try to understand and build on where there is agreement, and creatively respond to differences.

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DEFINITION

1. What are goals of care?

Goals of care are those life goals that pertain to patients' health and well-being, and are therefore critical in helping them make informed decisions about their medical care.[1,2] Patients' personalities, dreams, hopes, and personal values all play a role in defining their life goals. Patients or families may have multiple goals of care simultaneously, and at times these goals may seem contradictory.[1] For example, patients may express a desire to prolong life with chemotherapy for cancer, and at the same time express aversion to anything that could cause suffering. Some goals may take priority over others, and some may change as life circumstances evolve, for example, from well-compensated chronic illness to end of life. **Fig. 1** shows this spectrum of goals of care.[3]

BACKGROUND

1. How have goals-of-care discussions evolved through history?

During the last century, the focus of medicine shifted from comfort to a more curative focus.[1] Running parallel to this paradigm shift was the change in the doctor-patient relationship from a paternalistic approach to one of shared decision making.[4,5]

Before the twentieth century, the practice of medicine followed a model of beneficence that had changed little since Hippocrates.[5] Under this model, active patient participation in medical decisions was not valued. In the twentieth century, rapid developments in scientific rigor and technology widened the knowledge divide between trained clinicians and patients, leading to even less patient participation, with the attitude the doctor knows best. Likewise, clinicians frequently made decisions for their patients without their input, in their best interest, so as to prevent serious harm under the accepted principle of benevolent deception.[4,5]

In the last 40 years, this paternalistic approach changed rapidly to a model of shared decision making between the patient and the clinician.[4,6,7] The reasons for this paradigm shift are complicated but in particular can be linked to a rapid advancement in technology and medical knowledge, making possible more interventions/treatments than ever before, as well as a new emphasis on patient autonomy and a need for patients to actively engage in the medical decision-making process with their clinicians.[6,7] For this partnership to be successful, it is critically important that patients as well as clinicians fully understand each others' perspectives, including an understanding of patients' goals of care in light of their medical condition.[4,8,9] This is particularly important as patients become more seriously ill, potentially nearing the end of life.

Fig. 1. Spectrum of goals of care.

2. Why are goals-of-care discussions necessary to ensure the medical well-being of patients?

Advances in medical knowledge and technology in the last century have led to a multitude of treatment options and, in some cases, the potential for cure and eradication of diseases.[6] There has been a rapid increase in the burden of chronic illness as opposed to discrete, acute episodes of illness; nearly half of all Americans today live with some degree of chronic disease.[10] Many patients with chronic illness experience frequent medical visits, multiple medications, and significant lifestyle changes that are easier to adhere to (and thus are more successfully treated) if care plans are individualized.[6,10–12] Without explicit delineation of patients' values and goals of care, clinicians may make incorrect assumptions that result in unwanted treatment, potentially unnecessary suffering, or nonadherence to potentially life-prolonging treatment.[13]

3. Are there goals of care common to seriously ill hospitalized patients who are potentially nearing the end of life?

Although goals of care are individualized, there are 6 broad goals of care frequently cited by seriously ill hospitalized patients who may be nearing the end of life.[14] A focus on quality-of-life maintenance and independence is the most common.

1. Improve or maintain function/quality of life/independence (78.2%)
2. Be comfortable (32.6%)
3. Be cured (30.6%)
4. Live longer (10.6%)
5. Achieve life goals (7.7%)
6. Provide support for family/caregiver (2.9%)

FACILITATING GOALS-OF-CARE DISCUSSIONS

1. What is a framework for facilitating goals-of-care discussions and what skills might be helpful?

Goals-of-care discussions must be individualized depending on the values and priorities of each patient and/or family, and the interactive style and skill of the clinician. A one-size-fits-all formula is not feasible for conducting such discussions.[8] However, there are foundational elements and communication skills common to all goals-of-care discussions.[1,15] **Table 1** summarizes a framework for clinicians to use in leading goals-of-care discussions. This framework is a simplified model that weaves 3 basic communication skills throughout a conversation about diagnosis, prognosis, personal values, and treatment options. It need not be followed dogmatically, but provides a conceptual framework that clinicians can adapt to their personal styles and their patients' individual circumstances.

2. How are the communication skills noted in **Table 1** *used in facilitating goals-of-care discussions and simultaneously building therapeutic relationships?*

Ask-Tell-Ask helps the clinician to not only seek active patient participation and better understand the patient experience but it also allows the clinicians to share their knowledge and values and to ensure they are understood. The skill of Tell me More enables patients or families to expand on their personal values and allows clinicians to explore the patient perspective, thereby more fully understanding how patients are thinking

Table 1
Goals-of-care elements and skills

Step	Elements	Communication Skills
Set the stage	Gather participants Find a quiet space Sit down	Ask-Tell-Ask Tell me more Respond to emotion
Invite participation	Develop a common understanding of diagnosis, prognosis, personal values	
Make a recommendation	Recommend best treatment options in light of that common understanding	
Summarize	Recap decisions made Arrange follow-up meeting (if needed)	

and feeling about their situation. It can be helpful to ask patients (or families) to share vignettes that most exemplify what makes life meaningful to them. By allowing the clinician to more deeply engage and understand the patient, these skills help establish the beginnings of trust in a relationship that might have to rapidly face major life-and-death decisions.[16,17] **Table 2** lists these skills in more detail with some clinical examples.[16]

3. What are the foundational elements to every goals-of-care discussion?

Fig. 2 shows the basic elements that must be understood by both the patient and the clinician before being able to effectively define goals of care. Each element is sequential and builds on the one before it.

Table 2
Communication skills

Skill	Key Points	Examples
Ask-Tell-Ask	1. Ask for perceptions/questions 2. Tell what you know 3. Ask to check understanding	12. Ask: "Can you tell me what you already know about your condition?" 13. Tell: clarify and explain/enhance patient's knowledge 14. Ask: "Can you tell me your understanding of what we just talked about to be sure there is no misunderstanding?"
Tell Me More	Invite elaboration for further clarity and to elicit concerns as well as hopes	"You said you don't want to be a burden on your family. Can you say more about what being a burden means to you?" "You mentioned that you are afraid; can you tell me more about what you are most afraid of?" "Tell me more about what you are hoping will happen"
Respond to emotion	Legitimize Empathize	"Anyone in your shoes would feel upset" "I can only imagine how overwhelming this feels"

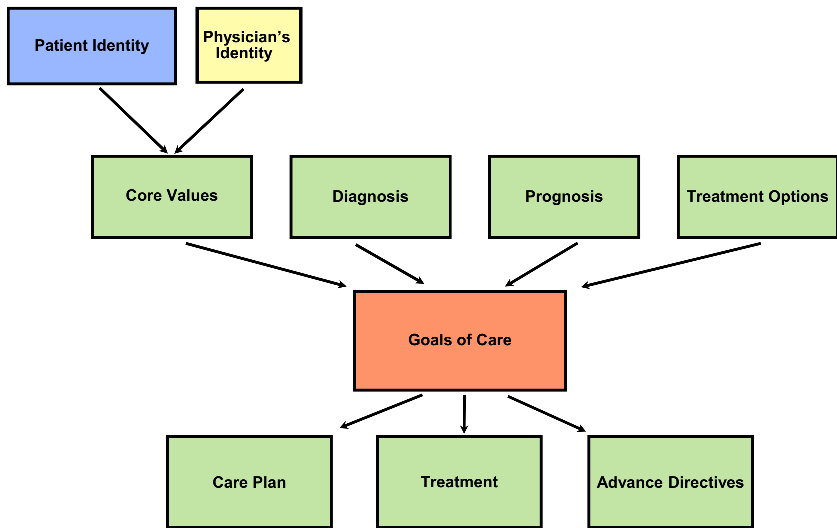

Fig. 2. Elements of goals of care.

THE DISCUSSION

There are several steps in the structural framework for a goals-of-care discussion.

Set the Stage

1. How should a clinician prepare for a goals-of-care discussion?

Clinicians must first understand their relationship with the patient and how their own medical identity (medical experiences, knowledge, and values) will play a role in the ensuing discussion.[4,18] Following this self-reflection, the clinician must determine appropriate participants and create an atmosphere conducive to conversation.

2. Why is it important for clinicians to understand their own medical identities?

By reflecting on their own medical experience, knowledge, and values before a goals-of-care discussion, clinicians can have a better understanding of how these experiences and values may influence the conversation, and of their own emotional responses to these discussions. Self-awareness not only helps the clinician better prepare, but may also allow the clinician to better guide the patient in navigating the complexities of medical decisions, and thereby help patients choose treatments that are more closely aligned with their own values and desires.[7,19]

Clinical example

A 96–year-old patient insists on wanting everything done. When explored further, the clinician learns that the patient would never want to be dependent on others for basic activities of daily living, and only wants everything done if she could go on living independently as she does now. The clinician's medical experience suggests that, given the patient's comorbidities, resuscitating her would most assuredly result in some form of disability if she survived at all. It is the clinician's responsibility not only to share this knowledge but also to help the patient understand that doing everything is not congruent with her desire never to be dependent on others.

3. How is the clinician-patient relationship different in the hospital?

Goals-of-care discussions for seriously ill hospitalized patients often occur in the absence of a long-standing relationship between the patient and clinician. For any complex discussion of this nature to be successful, the clinician must be able to rapidly establish trust with the patient, which can be challenging in the hospital setting. It is frequently impossible for the clinician to know much about a patient's identity before engaging in the goals-of-care discussion. Rather, the clinician may seek further understanding of the patient's preferences, experiences, and values throughout the goals-of-care discussion using the Ask-Tell-Ask and Tell me More. To do this well, the clinician must be vigilant about following up on particular statements and ensuring mutual understanding at each step in the process. For example, in the clinical scenario presented earlier with the elderly lady who wanted everything done, the clinician used the skill of Tell me More to more fully explore her individual reasoning and definition of having everything done. That process of exploration led to a better understanding of the patient's goals and priorities, thereby helping the clinician to guide the patient and family in choosing the best possible treatment plan under the circumstances.

Patients in the hospital are often cared for by a team of providers. Each clinician brings a unique set of values and experiences and, if acting in isolation, might give the patient contradictory messages. Depending on whether a clinician is a subspecialist or generalist, the direction of the conversation may be different. For example, a surgeon may offer a potentially curative treatment of a patient with localized lung cancer, whereas the hospitalist may not be able to fully support such an option when the patient's end-stage chronic obstructive pulmonary disease and poor functional status are taken into account. In such a situation, it is useful for the care team to speak with each other to identify a leader to guide the discussion.

4. Who are the active participants in the goals-of-care discussion?

In some cases, patients may defer decision making to their families, whereas others may prefer active involvement. It is important to ask the patients (or their surrogate decision makers if the patient does not have decision-making capacity) who they would like to participate in the meeting.[8] An example of how to initiate this conversation:

> *We have some serious things to discuss. Who else would you like to have present for this discussion?*

5. What sort of environment is best?

Although there are time and space constraints in the hospital, ensuring an environment that minimizes interruptions or distractions is a valuable investment for rapport building with the patient and family. A quiet, private area with space for all participants to sit down is ideal.

INVITE PARTICIPATION

1. How does the clinician engage the patient and family in a conversation about the diagnosis and prognosis?

Use the communication skill of Ask-Tell-Ask to gauge patient and family understanding, explain the disease process and physiology, and then check for understanding.

2. What is the importance of patient and family understanding of the diagnosis and prognosis?

It is important for clinicians facilitating the discussion to take time before goal setting to ensure that patients and their families have a good understanding of what lies ahead so that they are able to make well-informed decisions about treatment.[4,9]

3. How do clinicians explore their understanding of the diagnosis with the patient?

A goals-of-care discussion begins with a common understanding of diagnosis.[16] Jargon is a major barrier, both with the use of highly technical terms, or the assumption that patients and clinicians ascribe the same meaning to nontechnical terms. A casual use of the term kidney failure to describe prerenal azotemia might be interpreted as imminently fatal by a patient who had a family member die of kidney failure. An ideal way to arrive at a common understanding of diagnosis is to explicitly elicit perceptions with a question such as, “What is your understanding of what’s happening?” and then proceed with the Ask-Tell-Ask model.

4. How does the clinician explore the patient’s prognosis with the patient?

Clinicians must face questions such as, “Am I going to die?” or, “How long do I have to live?” Because of the discomfort and uncertainty involved, avoiding survival estimates may seem preferable to some clinicians. However, available literature indicates that many patients desire prognostic information.[14] Because most survival data are population based, absolute statements for individual patients (eg, “You have 6 months to live”) may be inaccurate. It is more useful to offer average survival estimates as ranges,[20] always allowing exceptions in both directions.

Table 3 lists some examples and pitfalls in assessing patients’ understanding of the nature and prognosis of their disease.

MAKE A RECOMMENDATION

1. Why is it important to make the distinction of realistic treatment options in light of patient values, priorities, and clinical realities?

Although technology and medical knowledge allow clinicians to offer extensive treatment options, some of them potentially cause suffering that may or may not be justified based on the patient’s identity and medical condition.[4,9] Framing treatment options within the patient’s predefined goals and values as well as balancing the options with the clinician’s medical knowledge helps patients understand all realistic treatment options, thereby allowing them to more effectively identify options consistent with their goals of care. For example, although chemotherapy and radiation therapy may be curative for lung cancer, a patient with poor functional status may be unable to tolerate the hardships of this therapy.

When defining realistic treatment options, it is also important to emphasize that disease-oriented and palliative goals may often be complementary instead of mutually exclusive. For instance, if patients feel better through palliative treatment, they may also be better able to sustain the rigors of disease-oriented treatment.[4] Using the earlier example, if the patient’s functional status improves with palliative treatment, then chemotherapy might become a more realistic treatment option.

Table 3
Exploring diagnosis and prognosis

Elements	Key Points	Examples	Pitfalls
Nature of disease	Ensures common understanding of the disease	Ask: "What is your understanding of what is going on with you?" Tell: Give manageable amounts information about the diagnosis and extent of disease using the patient's understanding as a starting point Ask: check back for patient understanding	2. Providing pathophysiology lectures/ medical jargon 3. Offering recommendations without first understanding patient perspective and experience
Prognosis	Ensures common understanding of the natural history and how treatment can change the disease course Helpful for planning and determining realistic goals	Ask: "Many people would like to know how much longer they may have. Would such information help you at this time? Tell: give an average range with exceptions in both directions "I expect most people with your illness to have a life expectancy of 1 to 3 mo. Of course, everyone is different, so some will live longer than this range and, unfortunately, some will also live shorter." Ask: "Can you repeat back to me what I just told you?" "Was that expected or a surprise?"	1. Avoidance of the discussion 2. Absolutism: "You have 6 mo to live"

2. Should the clinician offer a recommendation on which treatment option is best given patient values and clinical realities?

Clinicians need not fear that making a recommendation diminishes patient autonomy.[4] In making a recommendation, clinicians must incorporate what they have learned about the patients' values and priorities and their own knowledge of the effectiveness (or lack thereof) of various treatment options. By making their opinions explicit and empowering patients and families to voice their own preferences, clinicians foster a more open dialogue and negotiation process. They also help share the difficult burden of decision making with the patient and family.[21]

Ask: *"May I make a recommendation about the treatment that I feel best supports your values as I have understood them during this conversation?*

Tell: if permission is given, clinicians may then tell those options, explaining the benefits and burdens of each, including which option they think is best for the patient.

Ask: "I want to make sure I have explained this treatment well, including the risks and benefits. What is your understanding of what your life would be like during this treatment and what outcome you could hope to expect?"

3. How does the patient's identity (values, cultural influences, and life experiences) play a role in these discussions?

Creative collaboration identifies achievable goals tailored to personal values about what makes life meaningful. These goals must incorporate realistic hopes. Goals-of-care discussions for a patient nearing the end of life involve difficult decisions for which the patient may not immediately have an answer. To help patients arrive at a solution, the clinician must try to understand patients' identities as defined by their values, cultural influences, and life experiences. This understanding can then help the clinician guide the patient in making clinical decisions about treatment options and goals that are congruent with who the patient is as an individual. Disregarding the influence of these elements in patients' decision making frequently results in miscommunication or misunderstanding, and may contribute to seemingly unresolvable conflict between the clinician and patient.[8,9,17]

SUMMARIZE

Goals-of-care conversations are complex and may require more than one meeting to reach consensus. Decisions and agreements made should be summarized, and a follow-up meeting can be arranged as necessary.

NUANCES TO GOALS-OF-CARE DISCUSSIONS

1. Why is it important for the clinician to recognize and respond to an emotion?

At any point, strong emotions can emerge, and conflicts may arise as a result. A keen awareness of the patient's emotional response and a willingness of the clinician to revisit the discussion at a later time allow the patient some time to process the clinical information and consider the treatment options without being weighed down by emotions. Although cognitive content is important, emotional dynamics are just as critical in goals-of-care discussions. Responding to emotion is therefore a key communication skill to practice throughout the four steps. As indicated in **Table 1**, legitimizing and empathizing are two specific techniques that respond to emotion. Authenticity in these

Table 4
Responding to the patient's emotional response

Response to Emotion	Specific Example
Acknowledge	"You seem upset/sad/angry…"
Legitimize	"Anyone in your circumstance would be upset"
Explore	"Tell me more about the most upsetting part…"
Empathize	"I can only imagine that I would feel the same way if I were going through this…"
Follow through	"We are going to figure this out together…"

techniques often requires actively imagining the vulnerability of the patient's current experience. **Table 4** expands on these principles with some examples.

It is paramount for clinicians to understand their own emotional responses as well. Patients' experiences often trigger subconscious memories and emotions within clinicians. Although this allows clinicians to better empathize with patients, they must have control of this emotional response before engaging in further discussion with the patient. The following outlets can be helpful to clinicians to manage their own emotional responses:

- Find and share with a trusted colleague
- Explore within us; be mindful
- Share emotions with the health care team; most likely others have a similar response
- Develop a support group of colleagues to regularly discuss challenging cases

2. What are unintentional consequences of language?

Given that strong emotions may be evoked by goals-of-care discussions, language used by the clinician, both verbal and nonverbal, may have unforeseen meaning to the patient. Therefore clinicians must be self-aware of the language they choose to

Table 5
Be wary of language

Language with Hidden Meaning	What the Patient May Hear	More Inclusive Language
"Do you want us to do everything possible?"	"Of course I want everything–why wouldn't you do that?"	"We want to do everything we can to help, but we also want to avoid treatments that are more likely to harm than help"
"Should we refrain from extraordinary measures?"	"Don't I deserve extraordinary measures?"	"We want to avoid treatment that we think will do more harm than good"
"I'm going to make it so your father won't suffer"	"Can you guarantee me he won't suffer? Are you saying you are going to put him out of his misery?"	"We will do everything we can to keep him comfortable" "I want to ensure that your father receives the best possible treatment he deserves"

use with patients. Some examples of language that may imply abandonment to the patient are listed in **Table 5**.[22]

3. How is conflict within goals-of-care discussions approached?

Clinicians occasionally recommend a path that the patient and/or family adamantly oppose or, similarly, the proxy decision maker identifies a treatment plan that does not seem congruent with the patient's life wishes/goals. When such conflict occurs, the clinician should not view the participants as impeding the discussion but rather recognize that each member at the table has a right to different viewpoints,[23] and that the main challenge is to support what is known about the patient's own views, values, and decisions in light of the clinical circumstances. **Table 6** lists some approaches to resolving these differences using the following clinical example.

Table 6
Resolving differences of opinion

Steps to Resolving Differences of Opinion	Clinician's Language
Seeking common understanding	Tell me more: "Help me understand better why you are choosing this path. In my discussions with your grandmother, it seemed as if her independence was of utmost importance and that life was not worth living if this was taken away…" Ask: "What do you understand about what dialysis would entail and how your grandmother would feel on it?" Tell: describe the process of dialysis and ensure that the granddaughter understands what is involved Ask: "Knowing how this would affect her, what do you think your grandmother would choose to do in this situation?"
Define areas of agreement and disagreement	Agreement: "It seems that we are all in agreement that your grandmother would not want heroic measures such as CPR [cardiopulmonary resuscitation] if she were to naturally pass…" Disagreement: "Am I correct in assuming that we are still trying to figure out how aggressive we want to be with her kidney failure?"
Offer a second opinion	"Would it help to discuss your grandmother's situation with a kidney specialist?"
Take a time-out	"Let's obtain further information by speaking with the kidney specialists and give her another day to see if the diuretics improve her breathing, and then revisit the next step"
Offer a time-limited trial	Perhaps we can try dialysis to see how your grandmother tolerates it. It would be useful for you to accompany her so you can learn what it involves, and try to imagine how she would feel about it. We can revisit this decision in a week or two to see how she is responding decide whether to continue. If she is becoming less confused, she may be able to help us in this decision

Clinical Example

An independent 96–year-old woman was hospitalized after a fall. Her clinician was able to have a conversation with her early in the hospitalization and learned that life was not worth living for her if she would be dependent on others for her basic needs. Shortly after this conversation, she developed worsening renal failure as well as decompensated heart failure and delirium. It was difficult to balance the treatment of the heart failure with the renal failure, resulting in a need for dialysis if life-prolonging therapy was to be pursued. As an alternative, a plan devoted exclusively to her comfort was also a reasonable alternative under the circumstances. However, the patient was not able to participate in this conversation secondary to her delirium, and the decision fell to the patient's proxy who was her granddaughter. Although the granddaughter agreed that dialysis and admission to a nursing home were contradictory to grandmother's desire to remain independent, she asked that dialysis be pursued anyway.

SUMMARY

Goals-of-care discussions are vitally important in helping patients not only understand their care plans but in allowing them to actively participate in their own medical care. These discussions are a shared partnership between the clinician, patient, and family in which each partner works collaboratively to develop a care plan based on the patient's identity, values, clinical circumstances, and realistic treatment options. Although goals-of-care discussions are important throughout a patient's medical care, they are especially important as the patient becomes more seriously ill and potentially nears the end of life, because this is a time of uncertainty and emotional upheaval for the patient when priorities and goals frequently change.

ADDITIONAL RESOURCES FOR PRACTICING THESE SKILLS

Video examples

Useful video links with examples of goals-of-care discussions in different situations: http://www.youtube.com/palliumcanada

http://depts.washington.edu/oncotalk/videos/

Self-study modules on the Web

Northwestern University module on goals of care: http://endlink.lurie.northwestern.edu/eolc_goals_of_care.cfm

http://www.cancer.gov/cancertopics/cancerlibrary/epeco/selfstudy/module-9

Oncotalk: improving oncologists' communication skills: http://depts.washington.edu/oncotalk

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