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SAFE-GOALS: a protocol for goals of care discussions in the intensive care unit

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SUMMARY

Introduction In critical care, there is often a lack of understanding regarding patient preferences toward end-of-life care. Goals of care discussions are poorly defined and inhibited by clinician apprehension, prognostic uncertainty, and discomfort from both sides. In the delivery of bad news, protocol-based discussions have proven beneficial, yet no such protocol exists for goals of care discussions in the intensive care unit (ICU). We therefore assembled a multidisciplinary team to define a specific protocol dedicated to leading goals of care discussions in the ICU setting.

SAFE-GOALS protocol S: set up

A: acknowledgment F: family understanding E: events of hospital course G: get to know the patient O: options AL: active listening and discussion S: steps going forward

Conclusion This protocol provides a framework for leading goals of care conversations in the ICU. Specific training should be incorporated and better emphasized in the modern medical education.

INTRODUCTION

The intensive care unit (ICU) houses the most critically ill patients and is considered the pinnacle of care. It is a domain centered on multidisciplinary teams working together to ensure that needs are met, resources are appropriately allocated, and complications are minimized, especially as family members are often at the forefront of ICU rounds.¹ Equally important within the ICU are the 'goals of care.' This is classically defined as an understanding of the patient's priorities in the context of their illness and expected recovery.² Goals of care can be curative, rehabilitative, life-prolonging, or comfort focused. They should be derived based on the patient's expressed preferences, values, needs, concerns, and desires.³

The SUPPORT (the study to understand prognoses and preferences for outcomes and risks of trearments) trial in 1995 was one of the first to highlight the poor understanding we have of patient preferences surrounding end-of-life care.⁴ Less than half of providers knew if their patient preferred to avoid cardiopulmonary resuscitation (CPR). 'Do-not-resuscitate' (DNR) orders were often written late, with half being issued within 2 days of death. Significant resources were spent, as 38% of deceased patients spent ≥ 10 days in the ICU. Additionally, significant suffering was witnessed, with half of families reporting moderateto-severe pain for at least half of the time.⁵ Further studies have shown additional shortcomings, with only one-third of chronically ill patients having a goals of care discussion during hospital admission.⁶ Unfortunately, even among the frail, most adults have no prewritten Physician Orders for Life-Sustaining Treatment (POLST) and in the acute care setting a sizeable number of patients likely receive POLST-discordant care.⁷

There is evidence that early initiation of these discussions may lead to reduced length of stay, decreased ventilator days, and earlier transition to comfort care.⁸ Additionally, a multidisciplinary approach may be more effective with this transition.⁸ These conversations, however, are poorly defined and there may be a chasm between a patient's perception of a goals of care discussion and a clinician's report that it has been completed. In a clinic-based population, 66% of physicians reported having had a goals of care discussion, while only 52% of patients believed to have had one, suggesting a lack of clarity.9 There are numerous factors that may inhibit an effective goals of care discussion, such as clinician apprehension, prognostic uncertainty, lack of family contact, limited understanding of patient wishes, lack of family consensus, or discomfort from both sides.

In the delivery of bad news, protocol-based discussions have proven beneficial-such as the SUNBURN protocol for trauma and acute care surgery and the SPIKES protocol in medical oncology.^{10 11} Breaking bad news may be needed before or in conjunction with a goals of care discussion, but these protocols do not focus on making the decisions surrounding end-of-life care. The REMAP framework created a protocol for discussing long-term goals of care with medical oncology patients; however, it is structured for the outpatient setting rather than the acute inpatient domain.¹² The COMFORT protocol developed a novel narrative approach to breaking bad news.13 Its competencies (communication, orientation, mindfulness, family, ongoing, reiterative message, and team) were grounded in communication theory but difficult to learn and apply.14 Johns Hopkins later developed the Three-Act Model to simplify the narrative approach and apply it to a goals of care discussion.¹⁴ It involved three 'acts': (1) understanding the patient's story, (2) discussing medical opinion, and (3) making shared decisions. It was similar to the three-act structure of storytelling:

SAFE-GOALS

	S	Set Up Understand Events and Mentally Prepare What to Communicate Review Advanced Directives and Determine the Decision-Maker
	Α	Acknowledgement Introduce All Members of the Medical Team Recognize All Family and Friends Present
ŝ	F	 Family Understanding Appreciate What Information is Already Know Expand on Family Understanding and Clarify Preconceptions
	E	Events of Hospital Course Concisely Summarize Hospital Events Be Honest and Direct
	G	Get to Know the Patient Discuss Who the Patient Was Beforehand Focus on Personality, Independence, and Functionality
	G O	Discuss Who the Patient Was Beforehand
	G O AL	Discuss Who the Patient Was Beforehand Focus on Personality, Independence, and Functionality <i>Options</i> Discuss Options While Concentrating on the "Big Picture"

Figure 1 The SAFE-GOALS protocol.

set up, confrontation, and resolution. Although simplified and readily adaptable, it provided less in guidance for the actual conversation.

We therefore sought to create a more specific protocol dedicated to leading goals of care discussions in the ICU setting. A multidisciplinary team was assembled to define this protocol, including attending physician staff, critical care fellows, residents, critical care nurses, and palliative care providers. The development team was intentionally created to be broad and encompass perspectives from all practitioners commonly leading these difficult discussions.

The key concepts were identified from debriefs from what we have seen go well and what we have seen go poorly in these discussions. Subsequently, an intensive review of both the medical and palliative care literature regarding goals of care discussions was performed to help guide the protocol development. The first and last steps were adopted from both the SUNBURN and SPIKES protocols for breaking bad news, which emphasized the critical importance of starting with a proper set up ('set up,' 'setting,' respectively) and finishing by clarifying the steps going forward ('next steps,' 'summarize,' respectively). This protocol highlights the central steps needed for a goals of care discussion and the literature to support this methodology.

SAFE-GOALS PROTOCOL

The SAFE-GOALS protocol provides a framework for leading goals of care discussions in the ICU (figure 1). It is geared primarily toward conversations with family members for patients unable to make their own decisions but can be readily adapted to discussions with patients themselves. It is divided into eight sequential steps. However, these discussions are dynamic, and a physician should be able to adapt to the flow of conversation without being overly rigid. Rather than a mandatory checklist, these should be considered as ideas to incorporate as appropriate within the discussion. The protocol is defined as follows: S: set up

- A: acknowledgment
- F: family understanding
- E: events of hospital course
- G: get to know the patient
- O: options
- AL: active listening and discussion
- S: steps going forward

S: set up

The first step in a goals of care conversation is the set up and proper preparation can significantly influence the interactions. Set up and the coordination before the actual meeting is one of the most critical components in ensuring a successful conversation. The ICU will frequently involve emotionally charged events and decisions must be made that can be difficult for everyone involved, including the providers giving care. Before initiating the family interaction, a physician should take the time needed to compose themselves and be in a calm state of mind.

Before the discussion, review the chart to fully understand the precipitating events and clinical course. If consultants were involved, review their recommendations and advice. Be aware of all major events, surgeries and changes that have occurred. Although one does not need to memorize a set script, a physician should mentally prepare what they want to communicate. These complex discussions will often vary, but having a general format and planning ahead can keep the discussion successful and productive.

Review of any known advanced directive (living will or durable power of attorney for healthcare) should be considered mandatory before these discussions. Unfortunately, only one-third of adults in the USA have completed any type of advanced directive for end-of-life care.¹⁵ Additionally, advanced directives, even when written, are plagued by numerous shortcomings.¹⁶ Often, the document has not been physically given to staff and remains unavailable to the treating team. The information as well is often not clinically relevant or specific. Despite these deficiencies, advanced directives can often provide a frame of reference.

The official decision maker should be determined before these discussions begin, recognizing that states may have different laws and regulations.¹⁷ Understanding the surrogate medical decisionmaking hierarchy is of the utmost importance when making such profound decisions. If capable, the preferred decision maker is the patient themselves. However, many patients in the ICU lack capacity. In such situations, the preferred decision maker is generally a legal durable Power of Attorney (POA) for Healthcare. If a POA is not available, the decision then defaults to the patient's next of kin. The order of authority falls from spouse to adult children, to parents, to siblings, and finally to any other relatives available. If no next of kin can be found, the decision may then require a public guardian. Variations may be seen in different states regarding allowance and priority of 'domestic partners,' 'chosen adults,' or 'interested persons' (friends). There are also differences in regulations regarding disputes among decision makers if a consensus cannot be reached such as 'majority rule.' Some states also have grounds for rebutting the authority of a default decision maker.

Consideration should be given to the members of the medical team present. Typically, these conversations should be led by the physician staff caring for the patient, but additional team members can provide invaluable support. The bedside nurse often spends more time with the patient and family members, allowing them to develop a personal bond that cannot be duplicated. They can support both the family and staff in facilitating a productive conversation. As the importance of palliative care has been increasingly realized, more and more hospitals have dedicated palliative care teams that can help during these difficult conversations.¹⁸ Occasionally, consultants being present can provide a specific expertise in the decision-making process, such as a neurosurgeon after a severe traumatic brain injury.

Ideally, a prefamily meeting huddle should be held immediately prior to the actual goals of care discussion.¹⁹ This gets the entire clinical team on the same page to avoid conflicting opinions and confusion. When disagreements arise, focus on the uncertainty and discuss what to do further to develop an opinion and in what time frame. These meetings should establish the leader, define roles, and discuss objectives.²⁰

Additionally, if not all family members are completely fluent in the spoken language a professional medical interpreter should be included. In-person interpreters are generally preferred over virtual interpreters but not always available, particularly for languages less common to the given area. These discussions are not appropriate if the receiver is not completely fluent and there may be a critical lack of medical terminology despite a conversational ability. Additional family and friends are struggling with the situation themselves and should not be used as they may not understand the terminology, they may mask meanings, or they may not exactly interpret as intended. Bilingual students and nurses should also be avoided if not professionally trained as they may be unable to appropriately convey the medical concepts. For such critical decision-making, everyone must be clear in what is being discussed.

Family and friends can provide an intimate bond that no stranger can duplicate.^{21 22} At the same time, in critical situation, groups have potential to grow in large numbers. While family and friends can be supportive, excessively large groups should be avoided. Crowds can be a distraction and detract from the attention and care provided to those most directly involved. The ideal group size may vary based on the clinical scenario, but the optimal size should be determined at the physician's discretion.

The physical setting should also be considered. A quiet room should be used to avoid distractions and allow total attention given to the discussions at hand. The room should be large enough to accommodate all parties with sufficient chairs and tissues available. A safe egress strategy should also be considered. Although rare, all team members should have easy access to exit the physical space in the case of a violent reaction. These conversations should happen in-person and not over the phone, if at all possible. As over half of communication is non-verbal, significant meaning is lost over the phone, both for the clinician and the family.²³

A: acknowledgment

A goals of care discussion, like any other conversation, should start with introductions and acknowledgment of everyone present. Too often, providers may feel nervous and jump straight into their speech. Even if everyone has already met, introductions remain an important first step and can help set the tone. Families will meet dozens of people and numerous providers throughout the hospital course. It can become easy to forget names and faces. Introductions clearly establish the medical team providing care and define roles. Additionally, asking all family and friends to introduce themselves helps everyone feel included and fosters a communicative environment.

As the conversation begins, a physician should be aware of their non-verbal behaviors. It has been estimated that communication is 55% non-verbal, 38% vocal, and only 7% from the actual words used.²³ Non-verbal manners are essential in establishing a sense of rapport.²⁴ The entire team should sit down and avoid standing by the door as if they are in a rush to leave. Sitting has been associated with improved perceptions of physician communication skills.²⁵ Avoid staring, but making consistent eye contact with everyone in the room improves a perceived sense of empathy. Speech with reduced pitch and rate can also be seen as more caring and sympathetic.²⁶

F: family understanding

Management of critical illness involves complex concepts. Medical literacy of family members can be highly variable, and these events are often confused by rumors and misconceptions. Even family members that have been at bedside the entire stay may not completely understand what is happening to their loved one. A question such as 'What is your understanding of what has happened?' helps to clarify the family understanding. All misconceptions and misunderstandings should be corrected so that everyone is starting from the same point. Additionally, this understanding allows a physician to tailor the conversation and emphasize the details that are individually necessary.

E: events of hospital course

After understanding events from the family's perspective, the physician should respond with a review of the hospital course from a medical standpoint. This is important to put details into context and help families appreciate what has happened and better understand the decisions going forward. The hospital course should be summative but concise. This can be difficult to accomplish for patients that have extended and complicated stays, but excessively long narratives can be difficult to follow and can lose track of the primary points. Be honest and direct, but not every single detail needs to be covered in this discussion. Concentrate on the 'big picture' and what is most important. The primary focus should be directed at major events, surgeries, and ultimately provide an explanation for why the care has progressed to this point.

During these difficult conversations, it is important for physicians to avoid excessive technical information and terms. Medical jargon can be jarring and cause misunderstanding of the clinical situation. Physicians speaking with jargon are described as causing confusion, too technical, and even uncaring, while physicians speaking without jargon are described as good communicators, approachable, and more empathetic.²⁷

G: get to know the patient

The most important factor in the medical decision-making process is the patient themselves. Every person is unique, with different life experiences, personalities, and wishes. Occasionally, the patient may have had prior discussions with family surrounding goals of care and wishes may be explicitly known. Unfortunately, however, this is all too infrequent. In these cases, it can be extremely beneficial to learn more about who the patient was before the admission. Were they already bedbound and living in a nursing facility or were they highly active and independent? What was important to them? Was there a passion in life they could not live without?

Although the care team will have intimate knowledge of the patient from a medical perspective, it is the family and friends who know who the patient truly was and is. Statements such as 'Now before we talk about what to do next, I want to get to know John a little better. What was he like before this?' can help bridge this conversation. It can often be beneficial to concentrate this discussion on their persona, independence, and functionality to set the stage for decision-making going forward.

O: options

Once the stage is set with an emphasis on the patient, the physician should review the options going forward. Options must be clear, understandable, realistic, and practical. Although specific topics vary, in the ICU, these formal conversations most often surround the decisions of code status, tracheostomy placement, and comfort care. Details should be simplified and direct. It should concentrate on the 'big picture' as an overabundance of information can be overwhelming, causing a loss of sight as to what is truly important. When discussing death, use the words 'dead' and 'death,' avoiding euphemisms such as 'passed away.' Although 'death' may feel harsh and some families do not want to hear it, trying to soften the blow with euphemisms belittle the finality of the situation and can create confusion.

When discussing code status, it is important to educate on what is involved. The public often has falsely high expectations after cardiac arrest. In the media, 46%-75% of patients regain spontaneous circulation, 67% survive to discharge, and poor medium-term to long-term outcomes are minimally depicted.²⁸ In reality, only 20%–25% of patients survive an in-hospital arrest and the majority of survivors have some degree of brain injury and impaired consciousness.²⁸ The act of chest compressions itself is also violent, often fracturing the ribs or sternum and damaging the lungs. There are times when the act is absolutely indicated and can save a life, but in already critically ill patients with likely morbid outcomes the act may be a futile gesture and only serve to prolong the dying process with additional pain when an otherwise peaceful transition may be more appropriate. Some family members may feel like anything other than a full code is 'giving up' on their loved one. It should be emphasized that DNR does not mean 'do not treat,' and that full care can still be attempted or continued to

help a loved one recover but if their heart stops beating, to let them die in peace. Due to the negative connotation that many associate with the term DNR, that 'do not' may imply a negative withholding and an 'all or nothing' choice, some prefer the term 'Allow Natural Death,' which focuses on what the patient is allowed to do at the end of their life and emphasizes the natural process.²⁹

When discussing DNR changes, it is even more complicated by the wide array of concepts and variable understandings. A DNR order is more than simply 'no CPR,' but unfortunately there are no well-defined or widely accepted definitions. There is minimal guidance and institutional policies vary. By our definition, a primary DNR order should include three things: (1) no chest compressions, (2) no defibrillation, and (3) no resuscitative medications after cardiac arrest. These three measures should be presented together as a bundle and not as individual options from a menu to pick-and-choose from. 'Chemically coding' without the immediate compressions leaves time where the heart is not perfusing, causing rapid brain injury and end-organ damage, further worsening an already tenuous condition. The three measures work together as functions of a singular procedure and should be presented as such. Do not intubate (DNI) should be a separate order but will often be discussed at the same time as DNR, described as a 'DNR-DNI.' Other orders that should be considered separate but may need to be discussed in certain clinical scenarios include cardioversion (when not defibrillating in arrest), vasopressor support, dialysis, tube feeding, and the use of blood products. Each of these should be individually discussed, when appropriate, and not assumed, which can lead to misinterpretations. Family and caregivers must both be completely clear on what resuscitative measures are being discussed regarding goals of care.

It can be useful to differentiate 'quantity' of life from 'quality' of life. When discussing life-prolonging care, it is important to be aware of the quality of life and long-term consequences beyond the isolated procedure or decision being discussed. For example, in patients undergoing tracheostomy that will be bedbound and ventilator dependent, risks go beyond the procedural risks of bleeding, infection, and damage to surrounding structures. Immobile patients are often plagued by muscle wasting, difficult pressure sores, blood clots, recurrent infections such as pneumonia, and even future heart attack, stroke, or death. Family may consider tracheostomy as the final step to allow their loved one to live out in peace, whereas it may be the first step down a long and difficult road that may be viewed as death-prolonging intervention. This quality of life is important to consider when making such decisions.

One of the most difficult aspects when discussing options can be determination of prognosis. There is no crystal ball and often the future is not entirely certain. It is the job of the physician to use their medical knowledge and experience to guide these discussions. Serving in the ICU, critical care physicians are more acquainted with the immediate negative effects of a severe medical event and less adept at determining the ultimate prognosis and final level of improvement that may take months to years. Physicians must be careful to avoid making definitive concrete statements if in fact the future is not as clear. Yet at the same time they must be careful to not give false hope or mixed messages. Sometimes, the answer may be as simple as 'we don't know'. Measures that can help include providing ranges (best/worst case and most/least likely), acknowledging uncertainty, and emphasizing the rapidly evolving nature of critical illness.²

AL: active listening and discussion

After reviewing options, it is important to discuss them through active listening. Active listening is when a physician hears what someone is saying and attunes to their thoughts and feelings, turning a conversation into an active, non-competitive, twoway interaction.³⁰ In clinical use, it has been shown to improve the impression of relative experiences and facilitate positive interpersonal relationships.³¹ It improves the clarity and understanding of communication to minimize misunderstandings and enhance team performance with an improved sense of empathy.³² Active listening involves three aspects: cognitive, emotional, and behavioral.³³ The cognitive aspect requires paying attention to and integrating all the information received, both explicit and implicit. The emotional aspect involves staying calm and compassionate while managing one's own reactions. The behavioral aspect involves conveying interest and comprehension, both verbally and non-verbally.

Strong emotional responses can be elicited in these circumstances. A physician must be able to recognize and respond to such reactions. The patient and family may be at different stages of grief (denial, anger, bargaining, depression, and acceptance) and the physician must be prepared to handle any situation. Take the time to listen and respond to these thoughts and feeling. This may seem difficult in a time when increasing workloads and demanding schedules make physicians feel the need to quickly move the conversation forward. It has been demonstrated, however, that explicitly focusing on emotional affect with more empathetic responses may actually decrease the time required for clinical conversations.³⁴ Validating emotions tells the family that they are being heard and cared for, allows family to process their own thoughts, and enables them to confirm or amplify the physician's understanding.³⁵ This can be done by expressions of empathy such as 'I am here for you' or 'we are all here to support them'. Feelings can be directly reflected: if family is struggling to decide, say 'it seems you are struggling to decide,' if family is crying, say 'I see you are crying'. Empathetic curiosity can be demonstrated by statements such as 'I'd like to know more about this' or 'please, tell me more about how you are feeling'. Families take risk when sharing emotions and physicians can support them through affirmation and respect by statements such as 'thank you for sharing that with me' or 'I'm glad you are talking to me about your feelings'.

Silence and physical contact are two potential tools that can be used to convey empathy. An invitational silence can be used to allow family time to process their emotions and invite them into a conversation.³⁶ At the same time, one must avoid an awkward silence dragging on too long while a well-meaning clinician thinks they should be 'using silence.' Families can struggle with strong emotions and may need the physician to more actively engage them in the discussion if they become lost in grief. Physical contact, such as holding a hand or touching a shoulder or upper back, is often a warm sign of support, while touching the face, knee, or thigh can violate personal boundaries and should be avoided.³⁷ Appropriate judgment must be used when it comes to physical touch, especially in various social and cultural environments.

Topics raised during a goals of care discussion can evoke strong emotions in the family and the medical team. A physician must recognize their own biases and expectations to minimize their influence. These discussions are about the goals and wishes of the patient and their family. Decisions may be made that a physician would not want for themselves or their own family members. They must balance their own opinions with the foundational principles of medical ethics: autonomy, beneficence, non-maleficence, and justice. At the same time, if a family directly asks, 'what would you do if this was your family member?', it is reasonable to answer directly and honestly.

Advanced directives, when available, can help guide these decisions, and reading the patient's own words can be powerful. However, all too often, these documents are not available. When families struggle, it can be helpful to reflect on prior discussions. While patient wishes may be explicitly known, families often have never discussed such 'negative' topics. Another helpful approach is to reflect on the patient's past reactions to someone else's illness. Did they approve or disapprove of another person's life-prolonging care, and what thoughts and emotions were elicited? Their reaction to another person's illness may provide insight into their own wishes.

Occasionally, family members may feel a sense of guilt when making decisions. They may believe that if they are not 'doing everything,' they are 'giving up' or 'killing them.' However, stopping interventions is not active euthanasia. In these situations, we are often performing uncomfortable interventions to keep the body functioning, while withdrawing care may allow natural processes to take over. Family members may feel an undue sense of burden, as if they are unilaterally deciding what they want. Helping them understand that it is not about their own desires, but rather about using substituted judgment to serve as the patient's voice and articulate what the patient would have wanted, can help alleviate these feelings. Keeping the focus on the patient—what they were like and what they would want—helps keep the discussion focused and productive.

S: steps going forward

Before ending the conversation, it is important to reiterate and summarize the next steps going forward. Family should leave with a clear direction and strategy, knowing what to expect next. They should understand that the medical team is presenting options. The ultimate decision is up to them and they have the right to change their minds. If code status is being changed, it should be made clear exactly what is being changed. If planning on tracheostomy, discuss when or what barriers may need to be overcome if not yet medically ready. If pursuing comfort cares, discuss timing and what the process will be like. However, not every goals of care discussion will end with definitive decisions being made. Sometimes the family will need more time to consider their options and discuss among themselves. In these cases, the physician should discuss when they plan on talking again. Along this line, a time-limited trial of intensive care may be discussed in which an agreement is made to continue care over a defined period of time to determine whether the patient improves or deteriorates along pre-identified outcomes.38 39 This can help struggling families that need more time while setting pre-identified goals to help focus the discussion and decisions going forward. At times, there may be more than one decision that needs to be made in defining goals of care, such as code status while family still need more time in discussing comfort cares. In such cases, again define options and discuss through active listening.

Finally, once the conversation has ended, the physician should consider leading a medical team debriefing.⁴⁰ On a busy service, team members often immediately depart, ready to move on to the next task. A team debrief can be quick but allows us to analyze our interactions. These debriefs can improve both personal and team functioning through constructive discussions of things done well and ways to improve. Additionally, they allow an opportunity to evaluate any unresolved emotions and enhance team unity.

CONCLUSION

Leading goals of care discussions can be one of the most challenging tasks for practicing physicians. Protocol-based delivery can provide support to help guide these difficult conversations. The SAFE-GOALS protocol provides a framework for leading these discussions in the ICU.

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