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Shared Decision Making in Intensive Care Units: An American College of Critical Care Medicine and American Thoracic Society Policy Statement

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Abstract

Objectives—Shared decision-making (SDM) is endorsed by critical care organizations, however there remains confusion about what SDM is, when it should be used, and approaches to promote partnerships in treatment decisions. The purpose of this statement is to define SDM, recommend when SDM should be used, identify the range of ethically acceptable decision-making models, and present important communication skills.

Methods—The American College of Critical Care Medicine (ACCM) and American Thoracic Society (ATS) Ethics Committees reviewed empirical research and normative analyses published in peer-reviewed journals to generate recommendations. Recommendations approved by consensus of the full Ethics Committees of ACCM and ATS were included in the statement.

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CONFLICTS OF INTEREST

Potential conflicts of interest for members of the writing group were reviewed based on ACCM standard operating procedure. No potential conflicts relating to the content of this statement were identified. Potential conflicts disclosed were: Dr. Kon is an Associate Editor for *AJOB* Empirical Research and receives funding from the Greenwall Foundation's Faculty Scholars in Bioethics program. Dr. Davidson holds a business license for a private education company, however has earned no income related to the topic presented in this statement. She also provides research-related volunteer services to AACN and STTI on topics not related to those presented in this statement. Dr. Morrison is a member of a data monitoring committee for Glaxo Smith Klein on research not related to the topics covered in this statement, is a speaker and committee member of the American Society for Bioethics and Humanities, and is an editorial board member for the American Academy of Pediatrics. Dr. Danis has professional relationships with the American Society for Bioethics and Humanities and the Society of General Internal Medicine not directly related to the topics covered in this statement. Dr. White receives grant funding from the Greenwall Foundation and from the Moore Foundation.

Main Results—Six recommendations were endorsed: 1) Definition: *Shared decision-making is a collaborative process that allows patients, or their surrogates, and clinicians to make health care decisions together, taking into account the best scientific evidence available, as well as the patient’s values, goals, and preferences.* 2) Clinicians should engage in a SDM process to define overall goals of care (including decisions regarding limiting or withdrawing life-prolonging interventions) and when making major treatment decisions that may be affected by personal values, goals, and preferences. 3) Clinicians should use as their “default” approach a SDM process that includes three main elements: information exchange, deliberation, and making a treatment decision. 4) A wide range of decision-making approaches are ethically supportable including patient- or surrogate-directed and clinician-directed models. Clinicians should tailor the decision-making process based on the preferences of the patient or surrogate. 5) Clinicians should be trained in communication skills. 6) Research is needed to evaluate decision-making strategies.

Conclusions—Patient and surrogate preferences for decision-making roles regarding value-laden choices range from preferring to exercise significant authority to ceding such authority to providers. Clinicians should adapt the decision-making model to the needs and preferences of the patient or surrogate.

Keywords

Decision Making; Intensive Care; Intensive Care Units; Critical Care; Resuscitation Orders

INTRODUCTION

Major critical care professional organizations recommend shared decision-making (SDM) as a central component of patient-centered care in the Intensive Care Unit (ICU) (1–4). However, clinical experience in the last decade suggests that there is confusion amongst clinicians and policymakers about what SDM is and when it should be used. Conceptual clarification is needed to ensure that decision-making is consistent with ethical principles and with patient/surrogate preferences. For example, if clinicians leave decisions largely to the discretion of surrogates without providing adequate support, surrogates may struggle to make patient-centered decisions and may experience psychological distress (5). Conversely, if clinicians make treatment decisions without attempting to understand the patient’s values, goals, and preferences, decisions will likely be predominantly based upon the clinicians’ values rather than the patient’s, and surrogates may feel they have been unfairly excluded from highly personal and consequential decisions for their loved ones (1–2).

Although numerous publications address SDM with patients in the outpatient setting, considerably less scholarship has focused on the context of acute life-threatening illness and on situations in which surrogate decision makers must make decisions for incapacitated patients. This is problematic for critical care clinicians for several reasons. First, distinct challenges arise in the acute care context, such as time pressure and the absence of pre-existing relationships among clinicians, patients, and families. Second, the vast majority of patients facing decisions near the end of life as well as many other critically ill patients lack decision-making capacity, requiring surrogates to act on their behalf (6). Involving surrogates in decision-making raises distinct psychological, ethical, and communication challenges compared to involving patients in decision-making. For example, family

members sometimes struggle emotionally to authorize decisions that will lead to the death of a patient or to changes in functional status and quality of life, even when those decisions are clearly consistent with the patient's preferences (7). In addition, some surrogates make errors due to projection bias, consciously or unconsciously making decisions based on their own values rather than the patient's values (8–11).

The purpose of this document is to endorse a definition of SDM that is clinically useful in the context of critical illness, clarify when SDM may be the most appropriate decision-making strategy, present the range of ethically acceptable models for partnerships in decision-making, and provide a set of skills to help clinicians create genuine partnerships in decision-making with patients/surrogates. Clinicians should be cognizant that the ability of critically ill patients to participate in decision-making often fluctuates over the course of their illness trajectory, and that patient and surrogate preferences regarding the decision-making process often changes over time.

The goal of SDM is to make treatment decisions that are medically appropriate and consistent with the patient's values, goals, and preferences. At times, such partnerships may fail to yield decisions that are acceptable to both the clinical team and to the patient/surrogate. Inability to reach mutually-acceptable decisions may be due to multiple factors including surrogate preference to withdraw life-prolonging interventions when the care team believes that prolonging such interventions is clearly in the patient best interest, patients/surrogates request for interventions that the care team believes are futile or potentially inappropriate, family request for bedside rituals that violate state health and safety codes, etc. In such cases, it is often helpful to enlist the assistance of clinical ethics consultants or others adept at conflict resolution. When the care team believes that patients or surrogates are requesting interventions that are futile or potentially inappropriate, clinicians may refer to the recently-published multi-organization consensus statement on responding to requests for futile and potentially inappropriate interventions in the ICU (12).

METHODS

This policy statement was developed through a collaborative effort of the ACCM Ethics Committee and the ATS Ethics and Conflict of Interest Committee. A writing group comprised of members of these two committees was formed. The writing group reviewed pertinent literature published in a broad array of journals including those with a focus in medicine, surgery, critical care, pediatrics, and bioethics. Members of the writing committee conducted their own searches of theoretical analyses and empirical evidence using the PubMed search engine to search the Medline database. The bibliographies of pertinent studies were also reviewed. This method of literature review was deemed appropriate because this document is a policy statement that relies heavily on theoretical analysis informed by available research data and not a practice guideline. Theoretical analyses and empirical data were discussed with the full ACCM and ATS Ethics Committees as recommendations were generated throughout the writing process. The Policy Statement was reviewed, edited, and approved by consensus of the full Ethics Committees of the ACCM and ATS. The Policy Statement was subsequently reviewed by the ACCM Board of Regents, peer reviewers from the ATS, the Board of Directors of the ATS, and the SCCM

Council. At each stage, the Statement was revised until approved by each body. The final version was approved by the ACCM Board of Regents, ATS Board of Directors, and SCCM Council.

1. DEFINITION OF SHARED DECISION-MAKING

Based on the definition proposed by the Informed Medical Decisions Foundation (13), ACCM and ATS endorse the following definition: *Shared decision-making is a collaborative process that allows patients, or their surrogates, and clinicians to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values, goals, and preferences.*

Shared decision-making, broadly defined as a process in which healthcare providers and patients or surrogates make medical decisions together (14), has been endorsed by critical care professional organizations (1, 3). There is ongoing conceptual debate, however, about whether the term “shared decision-making” should be precisely defined as including specific communication elements or whether SDM should be more broadly defined to encompass any form of decision-making that involves collaboration between providers and patients/surrogates. For example, some define SDM narrowly as including at a minimum information exchange followed by a deliberative process between the provider and patient/surrogate culminating in a joint treatment decision (15). Alternatively, others define SDM more broadly, considering any collaborative process in which patients/surrogates and clinicians work together to consider the patient’s preferences and the providers’ clinical knowledge and wisdom to fall within the scope of SDM. The latter interpretation focuses more on role negotiation and assumes that some elements of decision-making may be delegated (16). It is beyond the scope of this document to resolve the debate, and the recommendations contained herein are equally applicable to either conceptualization of SDM.

Ethical justification for creating partnerships with patients/surrogates in decision-making—Several ethical justifications exist for creating partnerships in decision-making between clinicians and patients/surrogates, rather than having either the clinician or the patient/surrogate make decisions in isolation. Clinicians have a legitimate role in decision-making because of their expertise in medicine and their knowledge of the range of medically indicated interventions. Further, because clinicians often have significant experience making difficult choices, including end-of-life choices, and have generally worked with many families to make such decisions, such expertise is often extremely valuable in the decision-making process. Involving patients in decision-making manifests respect for persons, which is a core ethical obligation of the medical profession. Further, involving patients ensures that the decisions made are consistent with their values, goals, and preferences.

When patients cannot actively participate in decision-making (as is common in the ICU setting due to injury, critical illness, and/or sedative and pain-relieving medications), several reasons justify involving surrogates in decision-making (17). First, doing so allows clinicians to learn of and incorporate patients' values and previously expressed treatment preferences, thereby manifesting respect for the patient as a person (18). Second, involving

family members in decision-making manifests respect for the family unit, which is a highly valued aspect of community in most societies. Finally, most patients want their families to be involved in their treatment decisions (19), and most surrogate decision-makers wish to be involved in some way (20–23). Of note, while the criteria for being a legally authorized representative of a patient are not addressed here, from an ethical standpoint, the term “family” is used here in a broad sense to include all individuals whom the patient considers family, whether related or unrelated to the patient, including those with whom the patient has a significant relationship and those who provide support to the patient (24).

Similarly, in the care of children, there is clear justification for building partnerships with parents and patients. We generally assume that parents make decisions based on their child's best interests unless there is substantial reason to think otherwise. Further, parents are granted broad legal authority to make decisions on behalf of their children unless those decisions are inconsistent with the child's best interests. The American Academy of Pediatrics (AAP) points out, however, that the clinician bears responsibility for decision-making as well, and the active participation of clinicians in decision-making for minors is necessary (25). Further, the AAP notes that direct involvement of the child in decision-making is often appropriate (25).

2. WHEN SHARED DECISION-MAKING SHOULD BE USED

Clinicians should engage in a SDM process to define overall goals of care (including decisions regarding limiting or withdrawing life-prolonging interventions) and when making major treatment decisions that may be affected by personal values, goals, and preferences (26–27). Table 1 lists examples of preference-sensitive decisions.

Once clinicians and the patient/surrogate agree on general goals of care, clinicians confront many routine decisions (for example, how often to check vital signs and laboratory tests, which fluids to administer, what antibiotics to use and at what dosages). It is logistically impractical and ethically generally unwarranted to involve patients/surrogates in each of these medical decisions. A partnership in decision-making requires that the overall goals of care and preference-sensitive decisions be made using a SDM approach, however once those goals are determined, the clinician has a fiduciary responsibility to use experience and evidence-based practice to implement appropriate testing and treatment. When important, preference-sensitive choices arise, clinicians should engage the patient/surrogate to provide an opportunity for SDM.

In all cases, someone on the treatment team should explain what care is being given and why (including the most routine procedures) in terms that are understandable to the patient and family. Such information-sharing may be facilitated by use of informational pamphlets and videos. In addition, since clinicians cannot ever fully anticipate what interventions will be acceptable or objectionable, it is advisable for the clinician to emphasize, at the initiation of the ICU stay, that the patient and family are welcome to ask questions.

3. DEFAULT SHARED DECISION-MAKING STRATEGY

ACCM and ATS recommend that clinicians use a “default” approach to SDM that includes active input from both clinicians and patients/surrogates at each of three key stages:

information exchange, deliberation, and making a treatment decision. Default strategies serve as a starting point which can subsequently be modified by contextual factors (28). By analogy, most physicians have a standard, default approach to managing common clinical conditions. For example, when intubating a patient's trachea, a clinician may routinely use a particular type of laryngoscope blade, muscle relaxant, and induction agent. These defaults can, and often are, modified based on the particulars of the individual case. Similarly, the default SDM approach should be modified based on the individual case and the specific needs and preferences of the patient/surrogate.

Using the recommended default approach, first, clinicians and patients/surrogates share with each other the information needed to make a patient-centered decision. The clinicians share information about the relevant treatment options and their risks and benefits. The patient/surrogate shares information about the patient's values, goals, and preferences that are relevant to the decision at hand. Often, incapacitated patients have never had conversations with loved-ones regarding their preferences in specific clinical scenarios; or if they have had such conversations, such discussions were often insufficient to fully inform decision-making (29). Even in such cases, family and friends often have an understanding of the patient's overall values and potentially the patient's expressed preferences in other scenarios that may be relevant. As such, a broad discussion of the patient's prior actions and decisions may be helpful in determining what the patient might prefer in the current situation, which can help inform the decision-making process.

Next, both clinicians and patient/surrogate share in deliberations about which option is best for the patient. There are numerous aspects of deliberation, such as sharing opinions, asking questions, correcting misperceptions, explaining one's perspective about why one option is preferable, and exploring the other person's perceptions. Finally, clinicians and patients/surrogates agree on the decision to implement (15). Although presented here as simplified, distinct steps, at the bedside the process is often complex and challenging.

Three reasons justify the recommendation to use this model as the default decision-making strategy. First, empirical research suggests that most surrogates of ICU patients prefer to share the authority and burden of decision-making with clinicians (20–23). Second, the involvement of clinicians both in providing information and in deliberating with patients/surrogates is appropriate because clinicians' expertise in understanding what treatment options exist, as well as their risks and benefits, is necessary for sound decision-making. Third, this model of decision-making facilitates clinician understanding of the patient as a person. Such understanding of the patient's values, goals, and preferences is essential for clinicians to make patient-centered treatment recommendations. When discussing how to approach decision-making with patients/surrogates, clinicians should also clarify that the SDM approach presented here as the default is only one possible approach, and clinicians should assist patients/surrogates understand other decision-making approaches (outlined below) as well so that the approach employed will most closely match patient/surrogate preferences.

4. MODIFYING THE DECISION-MAKING PROCESS TO MEET THE NEEDS OF THE PATIENT/SURROGATE

Patient and surrogate preferences for decision-making vary significantly; therefore clinicians should tailor the decision-making process to each individual case. While data suggest that the majority of surrogate decision-makers for critically ill ICU patients prefer a “middle ground” approach, a non-trivial minority prefer either significantly greater control in decision-making or prefer to cede control to clinicians (Table 2). When the surrogate clearly understands the patient's preferences and wants greater independence in decision-making, such independence in choosing from among the medically-acceptable options may be appropriate. Alternatively, when the surrogate has a strong emotional or psychological aversion to assuming decisional responsibility, a greater degree of clinician responsibility may be appropriate. Further, the decision-making process often needs to change over the course of the patient's ICU stay depending on the patient's decision-making capacity, patient/surrogate preferences, the clinical scenario, and the choices to be made (20, 22). For example, the patient/surrogate may wish greater control early in the ICU stay due to unfamiliarity with ICU providers compared to later in the ICU stay once clinicians have earned the trust of the patient/surrogate. Similarly, the patient/surrogate may choose to cede highly technical decisions to clinicians (e.g., the surgical approach employed) whereas the same patient/surrogate may want greater control in more value-laden choices. Of note, however, data demonstrate that even for value neutral choices some patients/surrogates prefer to participate in decision-making. Further, even for highly value-laden choices some patients/surrogates prefer to defer decision-making to the doctor (Table 2). As such, ICU providers should be familiar with, and skilled at, a wide range of acceptable decision-making approaches.

The ACCM and ATS support the right of patients and surrogates to choose from the various treatment options recommended by the attending physician when they wish to do so. In such a model, the patient/surrogate bears the majority of the responsibility and burden of decision-making. The clinician is obligated to understand patient values, goals, and preferences to a sufficient degree to assure that the medical implications of decisions are not in conflict with these values. In such cases, clinicians provide honest and complete information when discussing the range of medically appropriate options, however the authority and burden of decision-making rests with the patient/surrogate.

The ACCM and ATS also support the right of patients or surrogates to allow clinicians to guide decision-making, including decisions about forgoing life-prolonging interventions. As presented in Table 2, data suggest that nearly half of surrogates of critically ill patients prefer that physicians independently make some types of treatment decisions. In regard to value-laden choices, what limited data exist suggest that 75% to 85% of surrogates prefer to share responsibility for decision-making with clinicians or make decisions after considering the clinicians' recommendations. Further, while data suggest that approximately 10% prefer to make such decisions independently, another 5% to 20% wish to defer such decisions to clinicians (Table 2). Therefore, because one goal of shared decision-making is to match the patient or surrogate's preferred decision-making style, employing a clinician-directed decision-making model can be appropriate in some circumstances (16, 30–38). (NB: The

terms *informed non-dissent* and *informed assent* refer to similar models, both variations of the approach presented here, in which the patient/surrogate actively chooses to defer a specific decision to the clinician. Curtis and Burt use the term *informed assent* to emphasize that the surrogate makes an active choice to not disagree with the clinician's decision, however the surrogate need not actively assent to the clinician's decision (34, 38). Kon uses the term *informed non-dissent* to clarify that no affirmative agreement, either verbal or written, is required under this model (16, 35–37). The disadvantage of the term *informed assent* is that in pediatrics for the last 30 years "assent" has widely been used to indicate the affirmative verbal and/or written agreement of a minor who, due to age, lacks legal decision-making authority to provide consent for treatment or inclusion in research (25, 39). The disadvantage of the term *informed non-dissent* is that it may be interpreted as a passive process without an active role for the surrogate decision-maker. Regardless of the term used, the ACCM, SCCM, and ATS support the requirement that surrogates are informed and understand that they are making a choice to defer decision-making to the clinician.)

When using a clinician-directed decision-making model, clinicians should proceed according to the norms of shared decision making to discuss the medical condition, explain available treatment options, and elicit the patient's values, goals, and preferences. This conversation may reveal that the surrogate wishes for clinicians to make the final treatment decisions so that the patient can receive care consistent with his/her values without the surrogate feeling responsible for the decision. This approach requires great care to ensure that the surrogate's desire for a passive role is not due to remediable considerations (inadequate information, inadequate support from clinicians, etc.). Further, the clinician must ensure that the surrogate understands the specific decision at hand (i.e., not a blanket deferral of all decision-making) and agrees to let the clinician make this specific decision without having to explicitly agree to (and thereby take responsibility for) the decision. In doing so, the clinician should explain not only what decision the clinician is making, but also the rationale for the decision. The clinician must then explicitly give the surrogate the opportunity to disagree. If the surrogate does not disagree, it is reasonable to implement the care decision.

Clinicians should be aware of the potential problems with allowing surrogates to defer high stakes, value laden decisions to clinicians. Specifically, clinicians, who are in a position of power in the ICU, may inadvertently assume more authority than patients/surrogates wish. As such, clinicians must be vigilant to ensure they are not taking more authority than appropriate. Further, large studies have shown that clinician cultural and religious background can have a tremendous impact on decisions made in ICUs (40), and biases can have significant effects on patient care (41), therefore clinicians should take great care to foster an awareness of what biases their own values may introduce. Becoming aware of one's own biases during decision-making is important in order to remain open to the patient's and surrogates' values, goals, and preferences.

This model of deferring value-laden choices to clinicians is a decision-making model that is distinct from paternalism in several ways. First, this approach requires that clinicians understand the values of the patient and use those values to determine the plan of care. Second, patients/surrogates are given the opportunity to obtain as much (or as little) medical

information as they choose. Third, clinicians inform patients/surrogates of decisions and ensure that they understand that they may make a different choice and that such a choice will be supported by the ICU team (34–35, 37–38). In contrast, under a paternalistic model clinicians hold all decisional authority to the exclusion of patients/surrogates and make decisions based on their own judgment about what is best. In essence, under a paternalistic model the clinician *takes* control without the agreement of the patient/surrogate, while under a clinician-directed approach (as articulated above) the patient/surrogate *cedes* control to the clinician because the patient/surrogate prefers not to bear the burden of decision-making (however the patient/surrogate may take back control at any time).

5. KEY COMMUNICATION SKILLS TO CREATE PARTNERSHIPS WITH PATIENTS AND/OR SURROGATES IN TREATMENT DECISIONS

Even clinicians who fully embrace the importance of involving patients/surrogates in treatment decisions may sometimes struggle with how to accomplish this in practice. We therefore provide a summary of important communication skills to create effective partnerships with patients/surrogates in decision-making. It is important to note that there is considerable uncertainty regarding the best strategy to achieve the tasks described below; therefore this section is intended largely as a conceptual roadmap for clinicians, rather than as a set of clinician recommendations. The skills are organized according to the major tasks of collaborative decision-making. Table 3 summarizes important communication tasks and Table 4 contains sample language for each of the key steps. Clinicians should receive communication skills training to support these behaviors, either through residency or fellowship training, or through continuing medical education.

Establish a partnership with the surrogate—A strong partnership among clinicians, patients, and surrogates is a prerequisite of all collaborative models of decision-making. However, the context of acute critical illness makes it difficult to achieve this partnership. Clinicians often have no prior relationship with the patient or surrogate. Families are often overwhelmed by the acute impact of critical illness. Therefore, clinicians should invest time early in the ICU stay to build rapport with the patient and surrogate, preferably prior to the moment that decisions need to be made. One way to build partnerships is through formal family meetings. The ACCM recommends that family meetings with the multiprofessional ICU team begin within 24–48 hours of ICU admission, and should be scheduled at regular intervals and as needed (3). A focus on rapport building might include introducing the clinical team, naming the team leader, explaining the role of clinical team members, and expressing commitment to deliver care that is patient- and family-centered. Inviting the patient, surrogate, or family members to participate in daily rounds can also foster trust, understanding, and empowerment (3–4). In addition, including other members of the healthcare team in rounds and communication with the family may enhance communication and decrease conflict both within the clinical team and between the clinical team and family (3, 42–45). Family members should be asked about the best means to reach them since many families may find it difficult to be present in the ICU or waiting area on a regular basis and may nonetheless wish to hear regularly about the patient’s status. Families should also be asked whether they are comfortable speaking in the language that the clinician uses or would prefer to speak in another language and hence would need an interpreter. Families should be

encouraged to tell the team something about the patient's personal history along with any pertinent medical details in order for the clinical team to become familiar with the patient as a person.

Provide emotional support—Patients and surrogates of critically ill patients have high levels of psychological distress during the ICU stay. There is clear evidence that strong emotions such as fear and anxiety impair individuals' ability to process information, deliberate, and make trade-offs (46–47). Therefore, attending to emotions before and during decision-making may be an especially important step in achieving patient-centered decisions. Clinicians should make a deliberate effort to address surrogates' emotions. Acknowledging strong emotions and expressing empathy are two basic strategies to provide emotional support that have been associated with decreased anxiety and higher satisfaction (48–49).

Assess surrogates' understanding of the situation—Patients and surrogates may come to clinical encounters with varying levels of comprehension. This is especially true in ICUs when patients/surrogates have had conversations with multiple providers. Rather than beginning conversations by delivering an “opening monologue” we suggest that clinicians start by eliciting the patients'/surrogate's understanding of the medical situation, such as asking, “Can you tell me what you've heard about what is going on with your mother?” The advantage of this approach is that it allows clinicians to gauge the patient's/surrogate's level of comprehension, then tailor their delivery of information accordingly. In addition, such an approach may serve the goals of minimizing the amount of “talking at the patient/surrogate” and encouraging patients/surrogates to share their perspectives.

Explain the patient's medical condition and prognosis—Patients/surrogates need a clear understanding of the patient's condition and prognosis to meaningfully share in decision-making, however this goal is often not achieved. Data suggest that patients and surrogates in ICUs often have overly optimistic expectations about prognosis (50–52). Further, audio-recorded family meetings in ICUs suggest that clinicians often do not clearly convey important information about patients' prognosis, including risk of death, ventilator dependence, and severe long-term functional impairment (53–54), which may contribute to patient/surrogate misunderstanding of prognosis.

There is an extensive literature on how to effectively convey risk to patients, as well as ongoing debate about whether the goal should be to convey precise prognostic estimates or to convey the overall summary of risk information (55–58). Clinicians should routinely discuss key domains of prognosis with patients and surrogates, which may include the risks of short and long term mortality, ventilator dependence, functional impairment and cognitive impairment. We suggest as a starting point that clinicians use the “Ask-Tell-Ask” approach: 1) Ask: ask for permission to discuss prognosis; Tell: convey the prognostic information (details below); Ask: assess the extent to which the patient/surrogate understood the information (59). Table 4 contains sample language. In some cases, surrogates may refuse to discuss prognosis. Because at least a basic understanding of prognosis is essential for decision-making, particularly in potential end-of-life choices, surrogates who refuse to discuss prognosis should be educated about why this information is critical, and should be

given time to become comfortable discussing such difficult topics. If the surrogate's refusal to discuss prognosis persists, an alternate surrogate decision-maker should be identified or the clinician should seek consultation from the clinical ethics consultant.

There is a paucity of evidence regarding how to effectively convey prognostic information. Two recent studies in ICUs suggest that using numeric statements to convey prognosis is not more effective than using qualitative statements, and both types of statements are frequently misunderstood (60–61). If clinicians choose to convey prognostic estimates by giving numerical risk information, clinicians should use whole numbers rather than fractions (e.g. “roughly 50 out of 100 patients with this illness die in the ICU”) and a consistent denominator (e.g., roughly 50 out of 100 patients with this illness die in the ICU; roughly 80 out of 100 have died by 6 months). Most importantly, because no method to convey prognosis is universally effective, clinicians should routinely check whether patients/surrogates have understood the prognostic information. One relatively nonthreatening way to do this is to ask the patient/surrogate how they are going to explain what they’ve just heard to other family members.

Highlight that there is a choice—Patients and surrogates may not be aware that there are several reasonable treatment pathways in the setting of advanced critical illness, including but not limited to full life support, a time-limited trial of ICU care, and a purely palliative approach to care. Audio-recordings of family meetings in ICUs reveal that time limited trials and purely palliative treatment pathways are often not explicitly discussed as reasonable treatment options (62–63). Clinicians should counter this by informing the patient or surrogate that 1) there is a choice, and 2) different patients may reasonably make different choices depending on what matters most to them. If clinicians are concerned that patients/surrogates will perceive this as a sign that the clinician is unprepared or uninformed, clinicians can convey that in order to respect patient’s preferences it’s important that the patient/surrogate share their perspective with the clinical team (64).

Explain principles of surrogate decision-making—When surrogates make decisions for incapacitated patients, they sometimes misunderstand their role in decision-making in two ways. First, surrogates sometimes believe that decisions hinge on purely technical medical judgments, and therefore underestimate the importance of their input to personalize care decisions to the patient’s values, goals, and preferences. Second, some surrogates mistakenly make decisions based on their own values or desires for the patient rather than the patient’s values; a type of projection bias (8–9, 65). Several communication behaviors may help overcome these problems. Clinicians should explain that most decisions in ICUs, especially those about goals of care, are value-laden and that the surrogate’s input is needed to select the treatment option that is best for the individual patients. It may also be helpful to explain the ethical goals of surrogate decision-making (66): for previously competent adult patients the goal should be to enact the patient’s previously stated treatment preferences if applicable and contemporary. An Advanced Directive, Living Will, or other document may assist surrogates understand what the patient believed he/she would want in cases of incapacity. (NB: Laws governing Advanced Directives, Living Wills, POLST/MOLST forms, Durable Powers of Attorney for Healthcare Decisions, etc. vary by state and country.

Clinicians should be cognizant of the laws governing such documents in their jurisdiction, and should educate surrogates as appropriate.) If the patient did not express such preferences, the goal is to make decisions that are respectful of the patient as a person, generally by trying to make decisions the patient would make if she could speak for herself (18, 67). For patients who have never had decision-making capacity (e.g., those with severe cognitive disabilities) and those who never articulated clear values, goals, and preferences; the goal should be to make decisions that are in the patient's best interest (32, 68–69).

In the case of critically ill infants and children, parents generally participate in decision-making on behalf of the patient. Clinicians should understand pertinent statutes and policies governing parental authority and medical decision-making, and must ensure they are partnering with the individual(s) who has the legal authority to make medical decisions for the child. In general, decisions should be based on the best interests of the child (25). At times, however, it may also be appropriate to consider how decisions will affect other family members and include such considerations in decision-making (70). If the parents make a decision that the clinical team believes is clearly inconsistent with the child's best interests, the team should take action to clarify decision-making (e.g., through a clinical ethics consultation) and potentially overrule the parents (e.g., through obtaining a court order).

Assess patient's/surrogate's role preference—The decision-making preferences of patients and surrogates is dynamic; changing as they become more accustomed to the ICU environment, dependent on the decisions at hand, and influenced by their relationship with various team members and their assessment of the care providers' skill and empathy and their level of comfort and trust in these individuals. One cannot simply ask patients and surrogates to explain their decision-making preferences upon ICU admission because they often do not appreciate their own decision-making preferences until faced with the reality of making a difficult choice (71–73), and the most appropriate decision-making model will change over time. As such, clinicians should discuss decision-making preferences in real-time as difficult decisions need to be made. Clinicians can use their prior interactions with the patient/surrogate, as well as the patient's/surrogate's prior experiences and decision-making preferences, to aid in discerning the patient's/surrogate's preferred decision-making model. Further, clinicians should draw upon their accumulated experiences with other patients and surrogates in attempting to match practice with the decision-making preferences of the patient/surrogate at that moment. Because decision-making preferences are mutable and often elusive, clinicians will make mistakes. While errors in judgment regarding which decision-making model to employ at a given time for a specific decision will inevitably occur, on balance the risk of such mistakes is outweighed by the risk of clinicians forcing patients/surrogates to bear more or less burden and authority in decision-making by relying solely on the default decision-making approach.

Explain treatment options—Clinicians should provide clear and complete information regarding the range of medically appropriate treatment options, including the risks and benefits of each option. Data show that clinicians frequently use medical jargon in communication with patients, and often do not explain the meaning of important terms (74–76). Further, even common terms such as "NPO," "pulse ox," intubation," and

“hypertension” are often misunderstood by patients and families (77). As such, clinicians must be vigilant and avoid use of all jargon when communicating with patients/surrogates, ask patients/surrogates whether they are confused by any of the terms used, and define any words that the patient/surrogate does not understand.

Elicit patient's values, goals, and preferences—When patients are able to communicate, even when they lack decision-making capacity, clinicians should elicit values, goals, and preferences directly from patients themselves. The opinions of patients should be sought whenever feasible, rather than assuming that they are too confused or sedated to contribute. Further, clinicians should obtain and review copies of any prior written statements (advanced directives, POLST/MOLST forms, durable power of attorney for healthcare decisions, etc.), and should communicate with family members, primary care providers, or other caretakers to understand any prior oral expressions of values, goals, and preferences.

Clinicians should also seek the input of family members and friends to better understand the patient's values, goals, and preferences even if no specific wishes were previously expressed. Because mortality is so hard to face for many people, most patients have never fully considered their values, goals, and preferences should they become critically ill, and even fewer have had serious discussions with loved-ones about these issues (29). Even in such cases, however, loved-ones often have a reasonable understanding of the patient's core values prior to becoming ill, and that information can be important in decision-making when the patient lacks capacity.

Because surrogates often mistakenly use their own values, goals, and preferences, rather than the values, goals, and preferences of the patient, when making choices, we recommend asking patient-focused questions, for example: “If your father could speak for himself right now, what do you think he would choose?”

Deliberate with patients and surrogates—To promote deliberation, clinicians and patients/surrogates should actively participate in back-and-forth discussions of the pros and cons of the various diagnostic and therapeutic options. Further, the thoughts and concerns of the patient, surrogate, and family members as well as those of the healthcare team members should be elicited and discussed openly. Clinicians can ask the patient, surrogate, and/or family members to explain the medical facts in their own words and can then correct any misunderstanding or misperceptions (78). Further, through open dialogue, not only can clinicians correct any misunderstanding or misperceptions on the part of the patient or family, but also the patient or family can correct any misunderstanding or misperceptions on the part of the clinical team. As such deliberations proceed, the clinician should generally offer to provide a recommendation that is based on an understanding both of the medical facts and of the patient's values, and should explain the rationale that underlies the recommendation so that patients/surrogates can clearly understand the basis for the recommendation and participate actively in decision-making. Recommendations should generally take into account the patient's values, goals, and preferences, however clinicians' judgment regarding what options are medically appropriate should be included. Clinicians should clearly articulate which recommendations are based solely on medical facts and

experience and which recommendations are based on personal beliefs and values. Clinicians should not underestimate the weight of their recommendations and should ensure that they do not inadvertently pressure or intimidate patients as choices are made (79).

Make a decision—Together, the patient/surrogate and clinician must decide what treatment plan to implement. The authority to decide from among the available, medically appropriate options rests with the patient/surrogate, however most patients/surrogates prefer to share that responsibility with clinicians, and some choose to cede authority to the clinician. When the patient/surrogate makes the decision, clinicians should consider repeating the decision back to the patient/surrogate to ensure that the decision is clearly understood. When the patient/surrogate and clinician share the responsibility and burden of decision-making, the clinician should clarify the decision and ensure that the patient/surrogate feels comfortable with the decision-making process. When the patient/surrogate cedes the responsibility and burden of decision-making to clinicians, clinicians must ensure that the patient/surrogate understands that such delegation may be revoked at any time and that the patient/surrogate may veto the clinicians' decisions without negative implications. (NB: This applies to decisions made when authority has been ceded to clinicians. When clinicians make purely technical decisions (e.g., the decision to not administer antibiotics to a patient with a viral illness), this veto power does not apply.)

6. FUTURE RESEARCH

There is a paucity of empirical data about the relative strengths and weaknesses of various approaches to involve surrogates in treatment decisions. High quality studies, including randomized controlled trials, are warranted to evaluate strategies to effectively involve surrogates in decisions for incapacitated patients including the use of decision aids, communication skills training for physicians, and the use of patient navigators/ decision support counselors and language interpreters. There are several important types of outcomes that should be assessed in such trials that can be roughly grouped as patient outcomes, surrogate decision-maker outcomes, healthcare utilization, and process measures recording the quality of decision-making.

RESPONSES TO POTENTIAL CRITICISMS

Some may be concerned that involving patients/surrogates in treatment decisions will mean that they can demand (and clinicians must provide) any intervention they want. This is a misperception. Clinicians are legally bound to practice within accepted standards of care, which entails helping patients/surrogates understand the range of medically accepted treatment options and choose from among those the one that is most consistent with the patient's values, goals, and preferences. Clinicians have ethical obligations to refrain from administering treatments or performing interventions that are outside accepted boundaries of practice, and to pursue a fair process of dispute resolution in cases in which there is legitimate uncertainty about the boundaries of accepted practice (12).

Second, some may be concerned that by allowing clinicians to bear the primary burden of decision-making (a clinician-directed approach as described above), clinicians will run afoul of statutes in states that bar clinicians from acting as agents for their patients. There is a

distinction, however, between clinicians being formally designated as an agent (e.g., through a durable power of attorney for healthcare decisions), which in some cases may violate statute, and clinicians taking an active role in decision-making. When clinicians bear the primary burden of decision-making, they are not acting as the patient's agent. In such cases, the patient or surrogate holds decisional authority and can exercise that authority at any time. Because the patient/surrogate can overrule the clinician's decision, the clinician does not hold decisional authority as would a duly appointed agent. As such, the models described here do not violate statutory requirements.

SUMMARY

Decision-making in the ICU involves choice-making for highly value-laden choices, value-neutral choices, and a range of choices between such extremes. Data suggest that patient and surrogate preferences for decision-making roles also range from preferring to exercise significant authority to ceding such authority to providers. Further, data suggest that while patient and surrogate preferences for decision-making roles may be influenced by the value-content of the choice at hand, some patients/surrogates prefer a very active role even for value-neutral choices whereas others prefer a very passive role even for some highly value-laden choices. As such, clinicians should adapt the decision-making model to the needs and preferences of the patient or surrogate regardless of the value-content of the choice. Accurately assessing the decision-making model that is preferred by the patient/surrogate at a specific time for a specific choice is extremely difficult, however allowing for many different models of decision-making, ranging from a patient- or surrogate-driven model to a clinician-directed model, is both ethically supportable and necessary to best match patient/surrogate choice-making preferences. Because data suggest that most patients/surrogates prefer an approach in which they and their clinician(s) are equal partners in decision-making, such a model should be used as the default, including elements specified above, and then the model should be adjusted to best match patient/surrogate preferences in decision-making approaches.

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REFERENCES

1. Carlet J, Thijs LG, Antonelli M, et al. Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003. *Intensive Care Med.* 2004; 30(5):770–784. [PubMed: 15098087]
2. Thompson BT, Cox PN, Antonelli M, et al. Challenges in end-of-life care in the ICU: statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003: executive summary. *Crit Care Med.* 2004; 32(8):1781–1784. [PubMed: 15286559]
3. Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. *Crit Care Med.* 2007; 35(2):605–622. [PubMed: 17205007]
4. Lanken PN, Terry PB, Delisser HM, et al. An official American Thoracic Society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses. *Am J Respir Crit Care Med.* 2008; 177(8):912–927. [PubMed: 18390964]
5. Gries CJ, Engelberg RA, Kross EK, et al. Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. *Chest.* 2010; 137(2):280–287. [PubMed: 19762549]
6. Prendergast TJ, Claessens MT, Luce JM. A national survey of end-of-life care for critically ill patients. *Am J Respir Crit Care Med.* 1998; 158(4):1163–1167. [PubMed: 9769276]
7. Majesko A, Hong SY, Weissfeld L, et al. Identifying family members who may struggle in the role of surrogate decision maker. *Crit Care Med.* 2012; 40(8):2281–2286. [PubMed: 22809903]
8. Fagerlin A, Ditto PH, Danks JH, et al. Projection in surrogate decisions about life-sustaining medical treatments. *Health Psychol.* 2001; 20(3):166–175. [PubMed: 11403214]
9. Marks MA, Arkes HR. Patient and surrogate disagreement in end-of-life decisions: can surrogates accurately predict patients' preferences? *Med Decis Making.* 2008; 28(4):524–531. [PubMed: 18566485]
10. Vig EK, Taylor JS, Starks H, et al. Beyond substituted judgment: How surrogates navigate end-of-life decision-making. *J Am Geriatr Soc.* 2006; 54(11):1688–1693. [PubMed: 17087695]
11. Torke AM, Alexander GC, Lantos J. Substituted judgment: the limitations of autonomy in surrogate decision making. *J Gen Intern Med.* 2008; 23(9):1514–1517. [PubMed: 18618201]
12. Bosslet GT, Pope TM, Rubenfeld G, et al. An official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units. *Am J Respir Crit Care Med.* 2015 submitted.
13. Informed Medical Decisions Foundation. What is Shared Decision Making?. cited Available from: <http://informedmedicaldecisions.org/what-is-shared-decision-making/>
14. Curtis JR, White DB. Practical guidance for evidence-based ICU family conferences. *Chest.* 2008; 134(4):835–843. [PubMed: 18842916]
15. Charles C, Whelan T, Gafni A. What do we mean by partnership in making decisions about treatment. *BMJ.* 1999; 319(7212):780–782. [PubMed: 10488014]
16. Kon AA. The shared decision-making continuum. *JAMA.* 2010; 304(8):903–904. [PubMed: 20736477]
17. Arnold RM, Kellum J. Moral justifications for surrogate decision making in the intensive care unit: implications and limitations. *Crit Care Med.* 2003; 31(5 Suppl):S347–S353. [PubMed: 12771581]
18. Brudney D. Choosing for another: beyond autonomy and best interests. *Hastings Cent Rep.* 2009; 39(2):31–37. [PubMed: 19388384]
19. Sehgal A, Galbraith A, Chesney M, et al. How strictly do dialysis patients want their advance directives followed? *JAMA.* 1992; 267(1):59–63. [PubMed: 1489360]
20. Heyland DK, Cook DJ, Rocker GM, et al. Decision-making in the ICU: perspectives of the substitute decision-maker. *Intensive Care Med.* 2003; 29(1):75–82. [PubMed: 12528026]
21. Anderson WG, Arnold RM, Angus DC, et al. Passive decision-making preference is associated with anxiety and depression in relatives of patients in the intensive care unit. *J Crit Care.* 2009; 24(2):249–254. [PubMed: 19327283]

22. Johnson SK, Bautista CA, Hong SY, et al. An empirical study of surrogates' preferred level of control over value-laden life support decisions in intensive care units. *Am J Respir Crit Care Med*. 2011; 183(7):915–921. [PubMed: 21037019]
23. Madrigal VN, Carroll KW, Hexem KR, et al. Parental decision-making preferences in the pediatric intensive care unit. *Crit Care Med*. 2012; 40(10):2876–2882. (NB: Published version presents pooled results. Unpooled data obtained from author via correspondence). [PubMed: 22824932]
24. National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines for quality palliative care, executive summary. *J Palliat Med*. 2004; 7(5):611–627. [PubMed: 15588352]
25. American Academy of Pediatrics; Committee on Bioethics. Informed Consent, Parental Permission, and Assent in Pediatric Practice. *Pediatrics*. 1995; 95(2):314–317. [PubMed: 7838658]
26. O'Connor AM, Llewellyn-Thomas HA, Flood AB. Modifying unwarranted variations in health care: shared decision making using patient decision aids. *Health Aff (Millwood)*. 2004; (Suppl Variation):VAR63–VAR72. [PubMed: 15471770]
27. O'Connor AM, Wennberg JE, Legare F, et al. Toward the 'tipping point': decision aids and informed patient choice. *Health Aff (Millwood)*. 2007; 26(3):716–725. [PubMed: 17485749]
28. Halpern SD, Ubel PA, Asch DA. Harnessing the power of default options to improve health care. *N Engl J Med*. 2007; 357(13):1340–1344. [PubMed: 17898105]
29. Schneider, CE. *The practice of autonomy: Patients, doctors, and medical decisions*. Oxford: Oxford University Press; 1998.
30. Beauchamp, TL.; Childress, JF. In: *Principles of Biomedical Ethics*. 5th ed.. New York, NY: Oxford University Press; 2001. p. 64
31. Loewy, EH.; Loewy, RS. *Textbook of Healthcare Ethics*. 2nd ed.. Boston, MA: Kluwer Academic Publishers; 2004.
32. Lo, B. *Resolving Ethical Dilemmas*. 2nd ed.. Philadelphia, PA: Lippincott Williams & Wilkins; 2000.
33. Thompson, DR.; Kaufman, D., editors. *Critical Care Ethics: A Practice Guide*. 3rd ed.. Mount Prospect, IL: Society of Critical Care Medicine; 2014.
34. Curtis JR, Burt RA. Point: the ethics of unilateral "do not resuscitate" orders: the role of "informed assent". *Chest*. 2007; 132(3):748–751. [PubMed: 17873188]
35. Kon AA. Informed nondissent rather than informed assent. *Chest*. 2008; 133(1):320–321. [PubMed: 18187769]
36. Kon AA. The "window of opportunity:" helping parents make the most difficult decision they will ever face using an informed non-dissent model. *Am J Bioeth*. 2009; 9(4):55–56. [PubMed: 19326316]
37. Kon AA. Informed non-dissent: a better option than slow codes when families cannot bear to say "let her die". *Am J Bioeth*. 2011; 11(11):22–23. [PubMed: 22047119]
38. Curtis JR. The use of informed assent in withholding cardiopulmonary resuscitation in the ICU. *Virtual Mentor*. 2012; 14(7):545–550. [PubMed: 23351289]
39. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. Research involving children. *Fed Regist*. 1978; 43(9):2084–2114.
40. Sprung CL, Maia P, Bulow HH, et al. The importance of religious affiliation and culture on end-of-life decisions in European intensive care units. *Intensive Care Med*. 2007; 33(10):1732–1739. [PubMed: 17541550]
41. Blair IV, Steiner JF, Havranek EP. Unconscious (implicit) bias and health disparities: where do we go from here? *Perm J*. 2011; 15(2):71–78. [PubMed: 21841929]
42. Truog RD, Cist AF, Brackett SE, et al. Recommendations for end-of-life care in the intensive care unit: The Ethics Committee of the Society of Critical Care Medicine. *Crit Care Med*. 2001; 29(12):2332–2348. [PubMed: 11801837]
43. Kendall EM. Improving patient care with collaborative rounds. *Am J Health Syst Pharm*. 2003; 60(2):132–135. [PubMed: 12561657]
44. Jacobowski NL, Girard TD, Mulder JA, et al. Communication in critical care: family rounds in the intensive care unit. *Am J Crit Care*. 2010; 19(5):421–430. [PubMed: 20810417]

45. Rappaport DI, Ketterer TA, Nilforoshan V, et al. Family-centered rounds: views of families, nurses, trainees, and attending physicians. *Clin Pediatr (Phila)*. 2012; 51(3):260–266. [PubMed: 21954304]
46. Pham MT. Emotion and Rationality: A Critical Review and Interpretation of Empirical Evidence. *Review of General Psychology*. 1997; 11(2):155–178.
47. Power TE, Swartzman LC, Robinson JW. Cognitive-emotional decision making (CEDM): a framework of patient medical decision making. *Patient Educ Couns*. 2011; 83(2):163–169. [PubMed: 20573468]
48. Fogarty LA, Curbow BA, Wingard JR, et al. Can 40 seconds of compassion reduce patient anxiety? *J Clin Oncol*. 1999; 17(1):371–379. [PubMed: 10458256]
49. Selph RB, Shiang J, Engelberg R, et al. Empathy and life support decisions in intensive care units. *J Gen Intern Med*. 2008; 23(9):1311–1317. [PubMed: 18574641]
50. Cox CE, Martinu T, Sathy SJ, et al. Expectations and outcomes of prolonged mechanical ventilation. *Crit Care Med*. 2009; 37(11):2888–2894. quiz 2904. [PubMed: 19770733]
51. Azoulay E, Chevret S, Leleu G, et al. Half the families of intensive care unit patients experience inadequate communication with physicians. *Crit Care Med*. 2000; 28(8):3044–3049. [PubMed: 10966293]
52. Rodriguez RM, Navarrete E, Schwaber J, et al. A prospective study of primary surrogate decision makers' knowledge of intensive care. *Crit Care Med*. 2008; 36(5):1633–1636. [PubMed: 18434916]
53. White DB, Engelberg RA, Wenrich MD, et al. The language of prognostication in intensive care units. *Med Decis Making*. 2010; 30(1):76–83. [PubMed: 18753685]
54. White DB, Engelberg RA, Wenrich MD, et al. Prognostication during physician-family discussions about limiting life support in intensive care units. *Crit Care Med*. 2007; 35(2):442–448. [PubMed: 17205000]
55. Fagerlin A, Zikmund-Fisher BJ, Ubel PA. Helping patients decide: ten steps to better risk communication. *J Natl Cancer Inst*. 2011; 103(19):1436–1443. [PubMed: 21931068]
56. Wilhelms EA, Reyna VF. Effective ways to communicate risk and benefit. *Virtual Mentor*. 2013; 15(1):34–41. [PubMed: 23356805]
57. Reyna VF. A theory of medical decision making and health: fuzzy trace theory. *Med Decis Making*. 2008; 28(6):850–865. [PubMed: 19015287]
58. Reyna VF. Theories of medical decision making and health: an evidence-based approach. *Med Decis Making*. 2008; 28(6):829–833. [PubMed: 19020341]
59. Buckman, R.; Kason, Y. *How to Break Bad News: A Guide for Health Care Professionals*. Baltimore, MD: Johns Hopkins University Press; 1992.
60. Lee Char SJ, Evans LR, Malvar GL, et al. A randomized trial of two methods to disclose prognosis to surrogate decision makers in intensive care units. *Am J Respir Crit Care Med*. 2010; 182(7):905–909. [PubMed: 20538959]
61. Zier LS, Sottile PD, Hong SY, et al. Surrogate decision makers' interpretation of prognostic information: a mixed-methods study. *Ann Intern Med*. 2012; 156(5):360–366. [PubMed: 22393131]
62. Schenker Y, Tiver GA, Hong SY, et al. Discussion of treatment trials in intensive care. *J Crit Care*. 2013; 28(5):862–869. [PubMed: 23768446]
63. Schenker Y, Tiver GA, Hong SY, et al. Association between physicians' beliefs and the option of comfort care for critically ill patients. *Intensive Care Med*. 2012; 38(10):1607–1615. [PubMed: 22885651]
64. Elwys G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med*. 2012; 27(10):1361–1367. [PubMed: 22618581]
65. Scheunemann LP, Arnold RM, White DB. The facilitated values history: helping surrogates make authentic decisions for incapacitated patients with advanced illness. *Am J Respir Crit Care Med*. 2012; 186(6):480–486. [PubMed: 22822020]
66. Brock DW. Good decisionmaking for incompetent patients. *Hastings Cent Rep*. 1994; 24(6):S8–S11. [PubMed: 7860280]

67. Brudney D, Lantos J. Agency and authenticity: which value grounds patient choice? *Theor Med Bioeth.* 2011; 32(4):217–227. [PubMed: 21509506]
68. *Deciding to forego life-sustaining treatment.* Washington, DC: US Government Printing Office; 1983. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.
69. Buchanan, AE.; Brock, DW. *Deciding for others.* Cambridge: Cambridge University Press; 1989.
70. Mercurio MR, Maxwell MA, Mears BJ, et al. American Academy of Pediatrics policy statements on bioethics: summaries and commentaries: part 2. *Pediatr Rev.* 2008; 29(3):e15–e22. [PubMed: 18310465]
71. Curtis JR, Tonelli MR. Shared decision-making in the ICU: value, challenges, and limitations. *Am J Respir Crit Care Med.* 2011; 183(7):840–841. [PubMed: 21474424]
72. Haward MFE, Murphy RO, Lorenz JM. Default options and neonatal resuscitation decisions. *J Med Ethics.* 2012; 38(12):713–718. [PubMed: 23180252]
73. Kon AA. Difficulties in judging patient preferences for shared decision-making. *J Med Ethics.* 2012; 38(12):719–720. [PubMed: 23180253]
74. Castro CM, Wilson C, Wang F, et al. Babel babble: physicians' use of unclarified medical jargon with patients. *Am J Health Behav.* 2007; 31(Suppl 1):S85–S95. [PubMed: 17931142]
75. Deuster L, Christopher S, Donovan J, et al. A method to quantify residents' jargon use during counseling of standardized patients about cancer screening. *J Gen Intern Med.* 2008; 23(12):1947–1952. [PubMed: 18670828]
76. Farrell M, Deuster L, Donovan J, et al. Pediatric residents' use of jargon during counseling about newborn genetic screening results. *Pediatrics.* 2008; 122(2):243–249. [PubMed: 18676539]
77. Fields AM, Freiberg CS, Fickenscher A, et al. Patients and jargon: are we speaking the same language? *J Clin Anesth.* 2008; 20(5):343–346. [PubMed: 18761241]
78. Farrell MH, Christopher SA, Kirschner AL, et al. Improving the quality of physician communication with rapid-throughput analysis and report cards. *Patient Educ Couns.* 2014
79. Parascandola M, Hawkins J, Danis M. Patient autonomy and the challenge of clinical uncertainty. *Kennedy Inst Ethics J.* 2002; 12(3):245–264. [PubMed: 12472078]

EXECUTIVE SUMMARY

Rationale

Although shared decision-making (SDM) between clinicians and patients or surrogates in intensive care units (ICUs) is broadly endorsed by professional critical care organizations, there remains confusion about what SDM is, when it should be used, and more broadly what approaches exist to effectively promote partnerships in treatment decisions.

Purpose

To endorse a definition of SDM, make recommendations about when a SDM process should be used, provide guidance on the range of ethically acceptable decision-making models, and provide a set of the communication skills clinicians should use to create effective decision-making partnerships.

Methods

The Ethics Committee of the American College of Critical Care Medicine (ACCM) and the Ethics and Conflict of Interest Committee of the American Thoracic Society (ATS) convened a writing group comprised of members of these committees. The writing group reviewed pertinent literature published in a broad array of journals including those with a focus in medicine, surgery, critical care, pediatrics, and bioethics and discussed findings with the full ACCM and ATS Ethics Committees throughout the writing process. Recommendations were generated after review of empirical research and normative analyses published in peer-reviewed journals. The Policy Statement was reviewed, edited, and approved by consensus of the full Ethics Committees of the ACCM and ATS. The Policy Statement was subsequently reviewed and approved by the ATS, ACCM, and Society of Critical Care Medicine (SCCM) leadership through the organizations' standard review and approval process.

Main Results

1. Definition of shared decision-making (SDM): ACCM and ATS endorse the following definition: *Shared decision-making is a collaborative process that allows patients, or their surrogates, and clinicians to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values, goals, and preferences.*

2. When SDM should be used: Clinicians should engage in a SDM process to define overall goals of care (including decisions regarding limiting or withdrawing life-prolonging interventions) and when making major treatment decisions that may be affected by personal values, goals, and preferences.

3. Default SDM strategy: ACCM and ATS recommend that clinicians use as their "default" approach a SDM process that includes the following three main elements: information exchange, deliberation, and making a treatment decision. Clinicians share information about the relevant treatment options and their risks and benefits, including the option of palliative care without life-prolonging interventions, and the patient or

surrogate shares information about the patient's values, goals, and preferences that are relevant to the decision at hand. Next, both clinicians and patient/surrogate share in deliberations about which option is most appropriate for the patient. Finally, clinicians and patients/surrogates agree on the decision to implement.

4. Modifying the decision-making process to meet the needs of the patient/surrogate:

Patients' and surrogates' preferences regarding participation in decision-making vary significantly. While data suggest that the majority of surrogate decision-makers for critically ill ICU patients prefer to share the responsibility and burdens of decision-making equally with clinicians, a non-trivial minority prefer either significantly greater control in decision-making or prefer to cede control to clinicians. Clinicians should therefore tailor the decision-making process for each individual and should adjust the process as needed over the patient's ICU course.

5. Key communication skills to create partnerships with patients and/or surrogates in treatment decisions:

Clinicians should be trained in the communication skills necessary to create effective partnerships in treatment decisions. Core categories of skills include: 1) establishing a trusting relationship with the patient/surrogate; 2) providing emotional support; 3) assessing patients'/surrogates' understanding of the situation; 4) explaining the patient's condition and prognosis; 5) highlighting that there are options to choose from; 6) explaining principles of surrogate decision-making; 7) explaining treatment options; 8) eliciting patient's values, goals, and preferences; 9) deliberating together; and 10) making a decision.

6. Future research: There is a paucity of empirical data about the relative strengths and weaknesses of various approaches to create partnerships in medical decisions. High quality research including randomized controlled trials are needed to evaluate various decision-making strategies, including the use of decision aids, communication skills training for clinicians, and the use of patient navigators or decision support counselors.

TABLE 1

Examples of preference-sensitive decisions in ICUs

1. Whether to undergo decompressive hemicraniectomy versus medical treatment in a patient with severe stroke and cerebral swelling.
2. Whether to convert a child from conventional mechanical ventilation to high frequency ventilation, which might decrease the risk of morbidity or mortality but which would necessitate deep sedation making it impossible for the child and her family to communicate.
3. Whether to pursue ongoing weaning efforts at ventilator facility or transition to palliative therapy for a patient with advanced COPD who has failed several attempts at ventilator weaning in the ICU.
4. Whether a patient's quality of life is sufficiently satisfying that she would want life-sustaining treatment when a life threatening event occurs.
5. Whether to attempt resuscitation in the delivery room and provide subsequent neonatal critical care to an extremely premature infant at the threshold of viability.
6. Whether to pursue a risky neurosurgical procedure to attempt to cure a child's seizures vs. continuing to treat with medications that may be impairing his performance in school.
7. Whether to proceed with palliative surgical procedures in an infant with complex congenital heart disease.

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Preferred Decision-Making Approach Among Surrogates of North American ICU Patients

Table 2

Decision-Making Model	Value-Neutral				Decision Type		
	Johnson(22)	Heyland(20)	Anderson(21)	Johnson(22)	Madrigal(23)	Value-Laden	
Surrogate decides independently	1%	1%	0%	10%	10%	10%	
Surrogate decides after considering physician's recommendation	10%	22%	25%	45%	30%	30%	
Shared responsibility for decision-making	27%	39%	58%	40%	45%	45%	
Physician decides after considering family's opinion	25%	24%	17%	3%	15%	15%	
Physician decides independently	37%	15%	0%	2%	5%	5%	

(20)Heyland *et al.*: Surrogates responded to questions regarding general decision-making preferences in 6 tertiary adult Med/Surg ICUs across Canada. (21)Anderson *et al.*: Surrogates of patients in medical and surgical ICUs at a tertiary hospital in Pittsburgh responded to questions regarding general decision-making preferences. (22)Johnson *et al.*: Surrogates responded to questions regarding value-neutral decisions (antibiotic choice) and value-laden resuscitation preferences in 3 adult ICUs in San Francisco. (23)Madrigal *et al.*: Parents of children in a tertiary pediatric ICU in Philadelphia responded to questions about decision-making preferences for very difficult, value-based choices.

Table 3

Key Communication Skills to Involve Patients or Surrogates in Treatment Decisions

Communication skill
<p>Establish a trusting partnership</p> <ul style="list-style-type: none"> • Meet regularly with patients and/or surrogates • Express commitment to patient and family • Involve interdisciplinary team in supporting the family
<p>Provide emotional support</p> <ul style="list-style-type: none"> • Acknowledge strong emotions • Convey empathy • Explore surrogate's fears and concerns
<p>Assess patient's or surrogates' understanding of the situation</p> <ul style="list-style-type: none"> • Ask open-ended question about what patient or surrogate has been told.
<p>Explain the medical situation</p> <ul style="list-style-type: none"> • Use simple language to explain patients illness • "Chunk and check" - convey information in small aliquots with frequent pauses to assess understanding • Convey prognosis for both risk of death and risk of functional impairment
<p>Highlight that there is a choice</p> <ul style="list-style-type: none"> • Explain that there is more than one reasonable treatment choice with different risks/benefits. • Explain why surrogates' input is important
<p>When necessary, explain surrogate decision-making</p> <ul style="list-style-type: none"> • Explain surrogate's role to promote patient's values, goals, and preferences. • Explain substituted judgment
<p>Assess patient's/surrogate's role preference</p> <ul style="list-style-type: none"> • Discuss patient's/surrogate's comfort making decisions at that moment • Explain the range of permissible decision-making models
<p>Explain treatment options</p> <ul style="list-style-type: none"> • Describe the treatment options, as well as their risks and benefits.
<p>Elicit patient's values, goals, and preferences</p> <ul style="list-style-type: none"> • Elicit previously expressed treatment preferences (oral or written) • Elicit patient's values about relevant health states • Ask surrogates what the patient would likely choose if he/she were able to speak for himself/herself.
<p>Deliberate with patients and surrogates</p> <ul style="list-style-type: none"> • Discuss the advantages and disadvantages of various diagnostic and therapeutic options • Explore patients' or surrogates' thoughts and concerns • Correct misperceptions

Communication skill
<ul style="list-style-type: none">• Provide a recommendation and explain rationale underlying recommendation
Make a decision
<ul style="list-style-type: none">• Agree on a treatment decision to implement

NB: There is considerable uncertainty regarding the best strategies to achieve the tasks described in the table. Clinicians should therefore consider these recommendations as a conceptual roadmap for clinicians, rather than as a set of clinician recommendations.

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Table 4

Example Language for Key Communication Skills

Communication skill	Example language for clinicians
Establishing a trusting partnership	"Hello, my name is Dr. Smith and I am the attending physician in the ICU. As your father's attending physician, I am ultimately responsible to the care he receives here. I have personally taken care of many patients with medical conditions similar to your father's. We have an outstanding team of nurses, respiratory therapists, pharmacists, and other professionals to give your father the best medical care possible. We also have excellent social workers, psychologists, and chaplains who can help you cope with the stress of having your father in the ICU. Many families have told me that having their father in the ICU is the most stressful experience of their life, and we will do everything we can to help your father and you during this time. I will personally work with you to make sure we are giving your father the kind of treatment he would want, and other members of the team with talk with you as well and give you the support you need. We will do everything we can to give your father the best treatment possible. Would you like to tell me a little about your father since I didn't get to meet him before he was so sick?"
Providing emotional support	"Many families of ICU patients tell me that they are having difficulty sleeping and eating, and many even find it difficult to take a shower or brush their teeth. These kinds of feelings can be very normal. I want you to know that everyone on the ICU team cares about you and your family, and we will do whatever we can to help you through this. If you ever want to just sit and talk, there is always a nurse or physician here to talk about your concerns, fears, and feelings. We can also schedule regular meetings for updates if that works well for you."
Assessing patient/surrogate understanding of the situation	"I know that you have already heard some information, and you probably have some understanding of your father's illness and just how sick he is. Before I start giving you more information, I would like to get a better sense of what you have been told and your impression of his condition. Can you please tell me what you understand about what is going on and how sick your father is?"
Explaining the patient's medical condition	"Everyone's brain needs to constantly get blood coming to it from the heart. The blood brings oxygen and nutrients to the brain through little vessels called arteries. Sometimes these arteries get clogged, and blood does not get to the part of the brain where that artery goes, and that part of the brain is injured or dies. Sometimes, that can be a very small part of the brain, but other times it can be a very large part of the brain. In your father's case, the MRI scan of his brain shows that the blood clotted in a large artery and a very large part of his brain died. When part of the brain dies, there is no way that it will recover. That means that even if your father survives, he will certainly have difficulty because the part of his brain that died controls his ability to speak and understand words. Unfortunately, we do not expect him to ever be able to speak again or understand what people say to him."
Explaining surrogate decision-making	"Because your father has had a bad injury to his brain, and because he has a breathing tube in and is on a lot of medications to keep him asleep and comfortable, he cannot make decisions for himself. When patients cannot make decisions for themselves, we work with a family member or a friend to make decisions for him. Your role will be to help us understand your father's values, goals, and preferences so that you and I can work together to make decisions for him. Our goal will be to make decisions that your father would likely have made for himself. Many families find it difficult to put aside their own values, goals, and preferences, but it is very important that you try to make decisions based on what you think your father would have chosen for himself."
Highlighting that there is a choice	"I know that we have talked about a lot of complicated medical information, but I wanted to make sure that you understood everything to the extent that you want because we need to make a decision about what to do next. I have taken care of a lot of patients in the same condition, and I can tell you honestly that different families make different choices. In a case like this, there is no "right answer." What we decide to do next depends on what your father would have wanted. There are some interventions that could potentially save your father's life, and some people prefer one of the options while others want the other option. It really depends on how your father would personally judge the risks and benefits of each. Also, I have taken care of many patients just like your father who believe that living without the ability to talk or to understand what their children are saying is simply not a life that is worth living. In those cases we decide that it would be better to stop some or all life-prolonging interventions such as the ventilator, or sometimes we decide to continue what we are doing but not add any new treatments. The goal at that point would be to make sure he is as comfortable as possible and not suffering. There is no right answer here, so we just need to talk it out and decide what makes the most sense for your father."

Communication skill	Example language for clinicians
Assess patient's/surrogate's role preference	"I've explained this to you because you are your father's next of kin, but every family addresses these issues differently. In general, we try to make decisions like this as a team, bringing together your understanding of your father's values, goals, and preferences and our knowledge of your father's injury and the various options. Now that we've discussed this a bit, I would like to talk about how comfortable you are making this decision together with me. I would also like to know if there someone else I should be speaking to as well. I have worked with a lot of families, and I have found that different people like to make decisions differently. Most families like to work together with me to share in the responsibility of decision-making, but some families prefer that I give them clear and honest information and allow them to make decisions on their own whereas others want to tell me about their father's values, goals, and preferences and then prefer that I make decisions for them. If you prefer to take the lead in decision-making, I will give you honest and complete information so that you can make the best decision possible. If you prefer that I make some of the difficult decisions, then I will give you as much information as you like and I will tell you what I plan to do before I do it so that you can tell me if you disagree with the decisions I am making for your father. Can you tell me a bit about how you think we should make these decisions for your father?"
Explaining treatment options	"The two options to try to prolong your father's life are a surgical intervention or a catheter intervention in radiology. Some people prefer the neurosurgical option because if the surgeon goes in and find the bleeding artery, he will almost certainly be able to stop the bleeding. The downside to the surgical option, though, is that it is very risky since the surgeon needs to go very deep into your father's brain. Others prefer the radiology approach because it is less risky, but the downside is that there is also a higher chance that the radiologist won't be able to stop the bleeding. I will explain the advantages and risks of each in much more detail if we decide that doing a procedure makes sense. As we discussed, some families believe that their father would not want to go through all of this to be left unable to speak and understand his family and friends. When families make that decision, we continue to provide high-quality care. If we decide that that makes the most sense for your father, we would continue to give him medication to make sure he is comfortable and in absolutely no pain. We would continue to take care of him and of you. We would make sure he is comfortable, and then we would take out the breathing tube. Once we take out the breathing tube, he would probably die fairly quickly. It is always impossible to know exactly how long a patient will live after the breathing tube is take out, but I have done this many times and in general patients die in about 15 minutes to 4 hours, although some die faster and others live longer. I have even had some patients live several more days or even weeks. However long your father lives after we remove the breathing tube, we would continue to take care of him and of you, and we would make sure his is comfortable and does not suffer."
Eliciting patient's values, goals, and preferences	"We've talked a lot about your father's condition and the choices we need to make. Because different people make different choices, I need to understand what is important to your father. What makes his life worth living? Knowing him, do you think that he would want to go through these treatments if he would never be able to speak or understand anyone ever again?"
Deliberating with surrogates	"Based on our conversation, I think that I have enough information about your father to make a recommendation. Before I do that, I want to make sure that you have as much information as you want and need. Is there anything I can clarify or any other information you would like? If not, then it is time for us to start thinking about what makes the most sense for your father. Based on what you have told me, it sounds like your father would want to remain alive as long as possible regardless of his ability to communicate. Based on that, I would recommend we move forward with the neurosurgical option because that option has the highest chance of keeping him alive. As we discussed, there is a very real risk that the neurosurgery will cause more damage to his brain, but it is the best option if the goal is give him the best chance to stay alive. What do you think?"
Making a decision	"Based on our discussion, it sounds like your father would not want to go through these procedures because no matter what happens he will never be able to talk or understand what anyone says to him and that is not a life that he would want. Based on that, it seems that it would be best for your father for us to make sure he is comfortable and then take out the breathing tube. We all understand that that means that he will likely die, but we will make sure he does not suffer. Are we all in agreement about that plan?"

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