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Making Medical Treatment Decisions for Unrepresented Patients in the ICU. An Official American Thoracic Society/American Geriatrics Society Policy Statement

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Journal

American Journal of Respiratory and Critical Care Medicine, 201(10)

ISSN

1073-449X

Authors

Pope, Thaddeus M Bennett, Joshua Carson, Shannon S et al.

Publication Date

2020-05-15

DOI

10.1164/rccm.202003-0512st

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AMERICAN THORACIC SOCIETY DOCUMENTS

Making Medical Treatment Decisions for Unrepresented Patients in the ICU

An Official American Thoracic Society/American Geriatrics Society Policy Statement

Thaddeus M. Pope, Joshua Bennett, Shannon S. Carson, Lynette Cederquist, Andrew B. Cohen, Erin S. DeMartino, David M. Godfrey, Paula Goodman-Crews, Marshall B. Kapp, Bernard Lo, David C. Magnus, Lynn F. Reinke, Jamie L. Shirley, Mark D. Siegel, Renee D. Stapleton, Rebecca L. Sudore, Anita J. Tarzian, J. Daryl Thornton, Mark R. Wicclair, Eric W. Widera, and Douglas B. White; on behalf of the American Thoracic Society and American Geriatrics Society

This official policy statement was approved by the American Thoracic Society February 2020 and the American Geriatrics Society January 2020

Background and Rationale: ICU clinicians regularly care for patients who lack capacity, an applicable advance directive, and an available surrogate decision-maker. Although there is no consensus on terminology, we refer to these patients as "unrepresented." There is considerable controversy about how to make treatment decisions for these patients, and there is significant variability in both law and clinical practice.

Purpose and Objectives: This multisociety statement provides clinicians and hospital administrators with recommendations for decision-making on behalf of unrepresented patients in the critical care setting.

Methods: An interprofessional, multidisciplinary expert committee developed this policy statement by using an iterative consensus process with a diverse working group representing critical care medicine, palliative care, pediatric medicine, nursing, social work, gerontology, geriatrics, patient advocacy, bioethics, philosophy, elder law, and health law.

Main Results: The committee designed its policy recommendations to promote five ethical goals: 1) to protect highly vulnerable patients, 2) to demonstrate respect for persons, 3) to provide appropriate medical care, 4) to safeguard against unacceptable discrimination, and 5) to avoid undue influence of competing obligations and conflicting interests. These recommendations also are intended to

strike an appropriate balance between excessive and insufficient procedural safeguards. The committee makes the following recommendations: 1) institutions should offer advance care planning to prevent patients at high risk for becoming unrepresented from meeting this definition; 2) institutions should implement strategies to determine whether seemingly unrepresented patients are actually unrepresented, including careful capacity assessments and diligent searches for potential surrogates; 3) institutions should manage decision-making for unrepresented patients using input from a diverse interprofessional, multidisciplinary committee rather than ad hoc by treating clinicians; 4) institutions should use all available information on the patient's preferences and values to guide treatment decisions; 5) institutions should manage decision-making for unrepresented patients using a fair process that comports with procedural due process; 6) institutions should employ this fair process even when state law authorizes procedures with less oversight.

Conclusions: This multisociety statement provides guidance for clinicians and hospital administrators on medical decision-making for unrepresented patients in the critical care setting.

Keywords: substituted judgment; surrogate; unrepresented; adult orphan; patient without advocate

Endorsed by the Society of Critical Care Medicine on January 24, 2020, and the Neurocritical Care Society on February 13, 2020.

ORCID IDs: 0000-0002-7163-505X (T.M.P.); 0000-0001-6220-7005 (S.S.C.); 0000-0003-4436-2209 (R.L.S.); 0000-0003-2269-4173 (D.B.W.).

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Am J Respir Crit Care Med Vol 201, Iss 10, pp 1182–1192, May 15, 2020 Copyright © 2020 by the American Thoracic Society DOI: 10.1164/rccm.202003-0512ST

Internet address: www.atsjournals.org

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Overview

ICU clinicians regularly face situations in which an adult patient lacks decision-making capacity, an applicable advance directive, and any available surrogate decision-maker (1–6). For these patients, there is no one with whom the clinician can engage in shared decision-making, which is recommended for important, value-laden decisions in ICUs (7). Available evidence shows that the absence of a decision-maker causes patients to face significant risks of being overtreated, undertreated, or otherwise treated inconsistently with their preferences and values (8–10).

This policy statement refers to these patients as "unrepresented patients." Yet, there is no consensus on which term to use, and others use "unbefriended" or "incapacitated patient without advocate" (11). In addition to terminology, there is considerable controversy over how to make medical treatment decisions for these patients (12). Moreover, in the ICU setting, there is significant variability in how decisions are made and little guidance about how to do so (2).

The committee developed this policy statement to help clinicians and hospital administrators design fair and feasible procedures for making treatment decisions for unrepresented patients in the ICU setting. This policy statement provides 1) an ethical analysis of medical decision-making for unrepresented patients, 2) recommended decision-making procedures for unrepresented patients in the critical care setting, and 3) proposed components of a model institutional policy on decision-making for unrepresented patients in ICUs.

The six recommendations described below have two primary justifications. First, they promote the following five ethical goals: 1) to protect highly vulnerable patients, 2) to demonstrate respect for persons, 3) to provide appropriate medical care, 4) to safeguard against unacceptable discrimination, and 5) to avoid the undue influence of competing obligations and conflicting interests. Second, the six recommendations help strike an appropriate balance between excessive and insufficient procedural safeguards. Excessive safeguards may delay providing patients with appropriate medical care and may be too cumbersome for clinicians and institutions. Insufficient safeguards may fail to adequately promote the five ethical goals.

Recommendation 1

Institutions should promote advance care planning to prevent patients at high risk from becoming unrepresented in the first place, both 1) by helping adult patients with decision-making capacity to identify a preferred surrogate decision-maker and to record their preferences and values in an advance directive and 2) by ensuring that such documents are available to clinicians at the point of care.

Recommendation 2

Institutions should implement strategies to determine whether seemingly unrepresented patients are, in fact, unrepresented by 1) carefully assessing medical decision-making capacity, 2) diligently searching for suitable surrogates among the patient's family and friends, and 3) involving any nonhospital individuals who have shown care and concern for the patient's welfare and are familiar with the patient's values and preferences.

Recommendation 3

Institutions should manage decisionmaking for unrepresented patients using collaboration between the clinical team and a diverse interprofessional, multidisciplinary committee rather than *ad hoc* by treating clinicians.

Recommendation 4

Institutions should use all available information on the patient's preferences and values to guide decisions. If such information is not available, the committee should collaborate with the treatment team to make decisions in the patient's best interest.

Recommendation 5

Institutions should manage decisionmaking for unrepresented patients using a fair process that comports with principles of procedural due process, such as transparency, legitimacy, and consistency.

Recommendation 6

Institutions should employ this fair process even when state law authorizes procedures with less oversight.

Introduction

ICU clinicians regularly face situations in which an adult patient lacks both decision-making capacity and any available surrogate decision-maker (1–6). For these patients, there is no one with whom the clinician can engage in shared decision-making, which is recommended for important, value-laden decisions in ICUs (7). Available evidence shows that the absence of a decision-maker causes patients to face significant risks of being overtreated, undertreated, or otherwise treated inconsistently with their preferences and values (8–10).

This policy statement refers to these patients as "unrepresented patients." Yet, there is no consensus on which term to use,

and others use "unbefriended" or "incapacitated patient without advocate" (11). There is considerable controversy over how to make medical treatment decisions for these patients (11, 12). Moreover, in the ICU setting, there is significant variability in how decisions are made and little guidance about how to do so (2).

Unrepresented patients in the critical care setting are common (5). In 2006, White and colleagues found that 16% of patients admitted to an ICU were unrepresented (1). In 2007, White and colleagues found that 5% of patients who died in the ICU were unrepresented (2). In a more recent survey of critical care clinicians and hospitalists, nearly 50% of respondents reported seeing at least one unrepresented patient per month (3). Other studies measuring the number of unrepresented patients in other healthcare settings corroborate these figures (4, 6, 13).

Incapacitated critically ill patients without an applicable advance directive or a surrogate decision-maker leave clinicians in a quandary. Providers in the United States generally take three different approaches: 1) providing treatment, 2) withholding or withdrawing treatment, or 3) delaying treatment. First, some clinicians might treat the patient without consent. Erring on the side of prolonging life, they may administer improperly prolonged life-sustaining treatment despite limited prospects of benefit, despite burdens on the patient, and even despite evidence of the patient's wishes to avoid such treatment (5, 14). Second, some clinicians might withhold or withdraw treatment because they unilaterally deem it to be potentially inappropriate. Third, other clinicians may delay treatment until the patient regains capacity or a court-appointed surrogate decision-maker is identified.

These inconsistencies are ethically problematic. Furthermore, this variability in care exposes unrepresented patients to three different types of risks: overtreatment, undertreatment, and delayed treatment. In addition, because there is no one to authorize discharge, the unrepresented often have prolonged hospital stays. ICU stays for unrepresented patients are often twice the duration of stays for other patients (9, 10).

Although several professional societies have published policy statements regarding decision-making for unrepresented patients (11, 15, 16), none specifically addresses decision-making for unrepresented patients in the critical care setting. Moreover, these

guidelines differ substantially on who may act as a surrogate and authorize treatment decisions on behalf of unrepresented patients (Table 1). State healthcare surrogate laws vary as well (Table 2) (3, 17–19). These conflicting laws and conflicting guidelines from professional societies are problematic. This variability may exacerbate confusion on this topic among clinicians, hospital administrators, and policy makers (15, 20–22).

Both because of these complexities and because clinicians need clear guidance, the American Thoracic Society (ATS) convened a multisociety working group to make recommendations regarding how to make treatment decisions for unrepresented patients in the context of acute critical illness. This ATS/American Geriatrics Society (AGS) policy statement provides clinicians and hospital administrators with guidelines for medical treatment decisionmaking on behalf of unrepresented patients.

The committee developed this policy statement to help clinicians and hospital administrators design fair and feasible procedures for making treatment decisions for unrepresented patients in the ICU setting. This policy statement provides 1) an ethical analysis of medical decision-making for unrepresented patients, 2) recommended decision-making procedures for unrepresented patients in the critical care setting, and 3) proposed components of a model institutional policy on decision-making for unrepresented patients in ICUs.

This policy statement focuses on decisions regarding life-sustaining treatment for adult patients. It does not address 1) decision-making for unrepresented patients outside the ICU setting, 2) decision-making for biomedical research purposes, 3) decision-making in emergencies, or 4) decisions regarding organ donation and other postmortem decisions. This policy statement also does not address decisions for minor interventions that are less consequential and may require less process and oversight (e.g., administration of most drugs and vaccines or the performance of minor procedures, such as routine X-rays) (7, 23).

Methods

An interprofessional, multidisciplinary expert committee developed this policy statement using an iterative process. The

ATS Ethics and Conflict of Interest Committee first convened an *ad hoc* working group composed of a subset of members of the ATS Ethics and Conflict of Interest Committee. The committee evaluated the need for additional expertise and invited 20 national experts to join the working group. The full working group was diverse and represented a breadth of disciplines, including critical care medicine, palliative care, pediatric medicine, nursing, social work, gerontology, geriatrics, patient advocacy, bioethics, philosophy, elder law, and health law.

The working group first reviewed known relevant literature, including journals with a focus in medicine, critical care, bioethics, and law. The group deemed this broad approach appropriate because this document is a policy statement that relies heavily on theoretical analysis informed by available research data and is not intended to be considered a practice guideline. The group also reviewed existing policies of other medical organizations. The group then developed the content of this policy through a 3-year iterative discussion-based consensus process consisting of face-to-face meetings, teleconferences, web conferences, and electronic correspondence. A writing committee drafted the policy statement, which the working group members then reviewed on multiple occasions and revised. The policy statement was further modified and ultimately approved by members of the ATS and AGS ethics committees. This statement then underwent a peer review process and ultimately review by both the ATS Board of Directors and the AGS Board of Directors.

Ethical Goals for Decision-Making for Unrepresented Patients

A review of the literature on unrepresented patients reveals five key reasons why guarded diligence and careful evaluation are required when making treatment decisions for unrepresented patients: 1) to protect highly vulnerable patients, 2) to demonstrate respect for persons, 3) to provide appropriate medical care, 4) to safeguard against unacceptable discrimination, and 5) to avoid undue influence of competing obligations and interests (Table 3).

Table 1. Existing Policy Statements Pertaining to Unrepresented Patients

Year	Author/Society	Decision-Maker
1992	New York State Task Force on Life and the Law	Interprofessional, multidisciplinary committee
2003	American Bar Association	Interprofessional, multidisciplinary committee
2006	Los Angeles County Medical Association	Interprofessional, multidisciplinary committee
2015	California Hospital Association	Interprofessional, multidisciplinary committee
2016	American Medical Association	Hospital ethics committee
2016	American Geriatrics Society	Institutional committee (e.g., ethics) or healthcare team according to a standardized process
2017	Veterans Health Administration	Interprofessional, multidisciplinary committee + chief of staff + facility director
2019	American College of Physicians	Court-appointed guardian

Protect Highly Vulnerable Patients

Unrepresented patients in the ICU are extremely vulnerable in several ethically relevant ways (24). First, patients in ICUs cannot advocate for themselves, because they frequently lack decision-making capacity owing to the severity of their illness and/or sedative and pain-relieving medications (7, 25, 26). Second, unrepresented patients lack trusted and reliable friends or family to advocate on their behalf. Third, when admitted to an ICU, patients (including unrepresented patients) usually lack a choice of healthcare clinician. They are completely dependent on the institution and its clinicians. For all these reasons, commentators have described unrepresented ICU patients as "unimaginably helpless" (27), as "highly vulnerable" (11), and as the "most vulnerable" (11).

Demonstrate Respect for Persons

Although manifesting respect for patient autonomy is a core principle of medical ethics, it is generally not applicable in the context of making decisions regarding lifesustaining treatment for unrepresented patients. This is because respecting a patient's autonomy requires the patient to have expressed an autonomous treatment preference applicable to the clinical situation at hand. By definition, unrepresented patients cannot currently articulate treatment preferences specific to the clinical decision at hand. Most have not done so previously, and even if they have, evidence of those preferences is usually not available (28).

This committee proposes that the broader ethical goal of manifesting respect for persons should be viewed as central to care processes for unrepresented patients. Respect in this context involves both the attitudes one adopts toward the unrepresented patient and the behaviors one manifests. Respect for persons requires an acknowledgment of each person's worth and dignity. The display of respect can take on numerous forms, such as making extensive efforts to learn about and treat the patient as a unique individual, incorporating all that is known about the patient's values into treatment decisions,

Table 2. State Healthcare Surrogate Decision Laws Pertaining to Unrepresented Patients

State	Decision-Maker
Connecticut, Nebraska, North Carolina, North Dakota, Oregon	Attending alone
Arizona, Arkansas, Louisiana, Tennessee, Texas Alabama California Colorado, Montana Florida Texas New York	Attending + second physician Attending + ethics committee Interdisciplinary team Medical proxy + ethics committee Independent clinical social worker Member of clergy Court

ensuring serious moral deliberation about decisions, and encouraging others to adopt a demeanor of sincere regard and caring for the person in all interactions.

Learning and incorporating the patient's individuality, values, goals, culture, and previously expressed treatment preferences manifests respect for persons, a core ethical obligation of the medical profession (7, 24). Physical harm is not the only type of risk posed to the unrepresented. Whether overtreated or undertreated, the unrepresented are susceptible to treatment decisions that do not conform to their personal values, morals, or beliefs. This is a serious affront to respect for persons.

The Institute of Medicine observes that patients "who have neither decisionmaking capacity nor a surrogate decisionmaker are at particular risk of not having their wishes known or followed" (8). For instance, several studies report that clinicians often make decisions based on their own idiosyncratic personal preferences. They may not know the patient, or they may not be willing and/or able to take the time to learn the patient's preferences (29, 30). A treatment decision that is not based on a patient's own preferences and values, when ascertainable, is particularly offensive in a society that places a premium on individual selfdetermination (7).

Provide Appropriate Medical Care

In addition to the risk of disrespect for persons, unrepresented patients face three types of treatment risk: overtreatment, undertreatment, or delayed treatment. In overtreated patients, the absence of an authorized surrogate often results in "maximum medical intervention, whether or not a medical 'full court press' is clinically and ethically warranted" (31). There are several reasons why the unrepresented receive unnecessary or unwanted treatment, including 1) clinicians' fear of not providing appropriate treatment, 2) fear of civil liability for failure to treat, 3) institutional fear of regulatory sanctions, 4) clinicians' economic incentives to treat, and 5) clinicians' general interventionist philosophy of medicine.

Most unrepresented patients are overtreated, but some are undertreated. With no surrogate to object, some clinicians may decide that treatment is inappropriate and unilaterally withhold or withdraw it.

Table 3. Five Ethical Goals for Safeguards in Decision-Making for Unrepresented Patients

- 1. Protect highly vulnerable patients
- 2. Demonstrate respect for persons
- 3. Provide appropriate medical care
- 4. Safeguard against unacceptable discrimination
- 5. Avoid undue influence of competing obligations and conflicting interests

Other clinicians may refuse to provide any type of treatment without informed consent. Consequently, important decisions may be "postponed dangerously [or] forgone altogether" (32, 33).

Some clinicians will wait until an emergency, when consent is implied and therefore there is no need for a surrogate to authorize treatment (3). However, waiting for an emergency may result in longer periods of suffering and indignity, increasing the chance of morbidity or even mortality. The absence of a surrogate can "stymie decision-making and possibly leave . . . patients to linger in pain and discomfort" (34). The Institute of Medicine found it ethically "troublesome" to wait "until the patient's medical condition worsens into an emergency so consent to treat is implied." Such an approach "compromises patient care and prevents any thorough and thoughtful consideration of patient preferences or best interest" (8).

Safeguard against Unacceptable Discrimination

Clinicians' treatment decisions may be influenced by medically irrelevant characteristics of the patient (e.g., the patient's race, gender, religion, social worth, undocumented immigration status, ethnicity, or sexual orientation) rather than by the nature of the medical service (35–40). It is unacceptable discrimination to treat a class of persons unequally on the basis of medically irrelevant characteristics. Such conduct is unethical and condemned by most health care professions' codes of ethics.

Not only intentional but also implicit biases may go unchecked without a surrogate to whom clinicians must explain and justify their recommendations (41, 42). The risk of unacceptable discrimination is especially germane, because unrepresented patients are often members of groups (e.g., homeless and those with mental illness

and substance use disorders) that have been subject to discrimination (43). Furthermore, there is a risk that treatment decisions will be influenced not only by irrelevant patient characteristics but also by irrelevant clinician characteristics, such as their own personal preferences for life-extending care or their religious beliefs (44, 45).

Avoid Undue Influence of Competing Obligations and Conflicting Interests

Competing obligations occur when clinicians have two or more valid professional responsibilities that conflict. Increasingly, clinicians are perceived to have ethical commitments both to individual patients and to society at large to manage resources in a cost-conscious manner. When clinicians act as decision-makers for their patients, there may be greater likelihood that the patient's interests are not adequately represented, considered, and balanced against the obligation to populations of patients (12, 46).

A related but distinct concern is that clinicians' real or perceived conflicts of interest may compromise their ability to act as decision-maker for an unrepresented patient. At least two types of secondary interests could unduly influence the clinician's professional judgment about the well-being of the unrepresented patient. First, financial interests of the clinician and/or institution could be affected by treatment decisions. For example, potential conflict could lead to overtreatment of patients in fee-forservice reimbursement models and to undertreatment in capitated models. Pressure to make scarce ICU beds available could also lead to undertreatment.

Second, clinicians face nonfinancial conflicts of interest. ICU clinicians generally work as part of an interprofessional, multidisciplinary team. To some degree, their professional satisfaction and advancement depend on good relationships with colleagues. End-of-life care often causes disagreement and moral conflict or distress among staff. Clinicians have an interest in maintaining cordial peer relationships and therefore in making decisions that will keep peace in the ICU. This will push toward overtreatment in some institutions and undertreatment in others.

Recommendations

Institutions should heed six recommendations outlined below (Table 4). They are designed to promote the five ethical goals. They are also intended to strike an appropriate balance between excessive and insufficient procedural safeguards. Excessive safeguards may unnecessarily delay providing patients appropriate medical care and may be too cumbersome for clinicians and institutions. Insufficient safeguards fail to adequately promote the five ethical goals.

Recommendation 1

Institutions should promote advance care planning to prevent patients at high risk for becoming unrepresented from meeting this definition, both 1) by helping adult patients with decision-making capacity to identify a preferred surrogate decision-maker and to record their preferences and values in an advance directive and 2) by ensuring that such documents are widely available to clinicians at the point of care.

Ideally, potentially unrepresented patients would engage in advance care planning in the community in places of worship, homeless shelters, social support agencies, legal aid offices, and primary care offices. Unfortunately, limited time and training constrain these discussions in the clinical environment. However, advance care planning can be effectively implemented in the hospital or ICU. Indeed, this is specifically mandated by the Patient Self Determination Act (47). Several studies found that although most ICU patients lack capacity, at least one-fourth remain involved with their treatment (37, 48). Many patients can name a surrogate after admission but before losing capacity (49).

Moreover, even if patients' capacity is impaired, they might still have capacity to share what they think about death, life, their current living situation, and their hopes for the future. In short, unrepresented patients should participate in making decisions to the extent that they can (50). Given that naming a preferred surrogate may not require as much decisional capacity as creating a living will expressing end-of-life treatment preferences, this "first step" in advance care planning should be encouraged upon admission or during periods of lucidity and documented when possible (23).

Table 4. Policy Recommendations for Medical Decision-Making for Unrepresented Patients in Intensive Care Medicine

Recommendation 1	Institutions should promote advance care planning to prevent patients at high risk for becoming unrepresented from meeting this definition, both 1) by helping adult patients with decision-making capacity to identify a preferred surrogate decision-maker and to record their preferences and values in an advance directive and 2) by ensuring that such documents are widely available to clinicians at the point of care.
Recommendation 2	Institutions should implement strategies to determine whether seemingly unrepresented patients are, in fact, unrepresented, including 1) carefully assessing capacity, 2) diligently searching for potential surrogates among the patient's family and friends, and 3) involving any nonhospital individuals who have shown care and concern for the patient's welfare and are familiar with the patient's preferences and values.
Recommendation 3	Institutions should manage decision-making for unrepresented patients using collaboration between the clinical team and a diverse interprofessional, multidisciplinary committee rather than <i>ad hoc</i> by treating clinicians.
Recommendation 4	Institutions should use all available information on the patient's preferences and values to guide treatment decisions. If such information is not available, the committee should collaborate with the treatment team to make decisions in the patient's best interest.
Recommendation 5	Institutions should manage decision-making for unrepresented patients using a fair process that comports with procedural due process, such as transparency, legitimacy, and consistency.
Recommendation 6	Institutions should employ this fair process even when state law authorizes procedures with less oversight.

Recommendation 2

Institutions should implement strategies to determine whether seemingly unrepresented patients are, in fact, unrepresented, including 1) carefully assessing capacity, 2) diligently searching for potential surrogates among the patient's family and friends, and 3) involving any nonhospital individuals who have shown care and concern for the patient's welfare and are familiar with the patient's values and preferences.

Assess capacity carefully. The best person to make healthcare decisions for the patient is the patient herself. With support, time, and good communication, some individuals who initially appear to lack capacity in fact may be able to make their own decisions (51). For example, language barriers, sensory deficits, and limited health literacy are sometimes confused with a lack of capacity. Too often, clinicians erroneously assess patients as lacking capacity to make their own treatment decisions.

Second, capacity is not all or nothing; it is decision specific. Several studies found that although most ICU patients lack capacity to make decisions about lifesustaining treatment, approximately one-fourth to one-third still have at least partial capacity (37, 48). For example, although patients may lack the capacity to make complex treatment decisions, they may have sufficient capacity to appoint a surrogate. Moreover, the ability of critically ill patients to participate in decision-making often fluctuates over the course of their illness trajectory (7).

Third, loss of decisional capacity may be transient. Delirium caused by infection, poorly controlled pain, sedating medications, or other substances may temporarily cloud the patient's decisional capacity. These conditions may be superimposed on psychological conditions such as grief, anxiety, or depression or sensory deficits such as hearing or vision loss. When feasible, it is preferable to delay important treatment decisions until reversible causes of impaired capacity are addressed (51). Search diligently for potential surrogates. For many individuals who are initially thought to be unrepresented, a diligent search often finds an available surrogate. Therefore, before enacting institutional or judicial mechanisms for the unrepresented, many state laws and medical society policy statements first require careful documentation of diligent efforts to locate family or close friend surrogates (52, 53). Processes include examining personal effects, health records, and other social services records (51). Other processes include searching social media, contacting neighbors, and even hiring a private investigator (33).

Family or close friends are preferred over institutional or judicial decisionmaking. First, they are more likely to know the patient's values and preferences (54). Second, involving family or a trusted friend in medical decisions is a highly valued aspect of community in most societies. Third, most patients want a trusted family member or friend to be involved in their treatment decisions (7). Fourth, most states include these individuals on a statutory hierarchical order of surrogate decisionmaking. For these reasons, the search for potential surrogates should be aggressive and rigorous (51). Even if a surrogate is not identified, this search process may reveal information about the patient's values and preferences that can guide treatment decisions (and is itself a manifestation of respect for persons).

Involve individuals who know and care for the patient. Clinicians can learn important information about a patient's preferences and values from people who are not willing or permitted to function as a surrogate. These individuals may know and care about the patient and can play a valuable role as "adviser" even if not as "decider." Consulting with these individuals is a way to ensure that all pertinent information about the patient is considered.

Unfortunately, many state laws are narrow and do not formally recognize some potential surrogates who may know and care about the patient (17). Some states recognize only a few types of family members. Some states do not recognize domestic partners or "close friends" to make decisions when no family member is available (55). Nevertheless, nearly 10% of patients select nonrelatives as their healthcare agents (56). Clinicians are often unfamiliar with these laws, which vary considerably from state to state (3, 57–59).

In fact, clinicians may seek the involvement of such nonhospital individuals, even when state law is too narrowly constructed to officially authorize them as surrogates (7). Although this is not specifically authorized, it is not prohibited. Furthermore, clinicians may seek relevant information from individuals who are uncomfortable with formally assuming the role of surrogate decision-maker.

Recommendation 3

Institutions should manage decisionmaking for unrepresented patients using collaboration between the clinical team and a diverse interprofessional, multidisciplinary committee rather than ad hoc by treating clinicians.

Risks of ad hoc decisions by treating clinicians. Commonly, treating clinicians assume sole decisional authority when caring for unrepresented ICU patients (6, 12). However, this is problematic for four key reasons. First, there is well-documented variability between clinicians in their judgments about what is appropriate care in such cases, raising the concern of undue variability in treatment decisions (60-65). Second, the perspectives of ICU clinicians about preferences for end-of-life care often differ significantly from the perspectives of patients and their family members (66-70). Third, removing the need for clinicians to justify or explain a treatment plan may eliminate an incentive to carefully consider the plan of care (12). Fourth, giving clinicians unilateral authority risks introducing bias and conflicts of interest. Indeed, most state laws prohibit hospital employees from serving as patientdesignated healthcare agents or courtappointed guardians for this very reason (71).

Advantages of an interprofessional, multidisciplinary process. Although entrusting decision-making to a single individual may be efficient, this advantage must be weighed against the plurality of views represented in a larger committee. In nonemergencies, institutional mechanisms are preferred to ad hoc strategies by clinicians because they can safeguard key elements of procedural fairness, including transparency, legitimacy, consistency, and the opportunity for appeal and review (72–74).

An interprofessional, multidisciplinary process will improve framing of decisions, putting specific clinical decisions at hand

into the broader context of what is known of the patient's values and goals and the likely prognosis relative to the burdens of interventions (e.g., what probability of recovery, to what level of health, in what time period, and with that burdens?). There are communication techniques that are employed with surrogates (e.g., best case, worst case, or most likely case) that can be extrapolated to diverse interprofessional, multidisciplinary committees to ensure that all relevant factors have been considered to explain to other people the clinical situation, the decisions at hand, and the reasoning behind the plan of care (75).

Procedural fairness is especially important, because the cases in question are often ethically controversial, have important interests at stake, and do not have explicit rules that can be mechanically applied (76, 77). Moreover, these cases inherently involve patients who are vulnerable by virtue of critical illness and incapacity and who have little choice regarding their treating clinicians. It is ethically important to incorporate multiple perspectives to minimize the risk that the values of any one individual carry undue weight. Within institutions, a process-based approach may lessen arbitrariness by ensuring broader input, consistency, transparency, and the possibility for continuous institutional learning about how to manage future cases (72, 78, 79).

There are several potential criticisms of institutional interprofessional, multidisciplinary management. Compared with *ad hoc* management by clinicians, institutional management strategies 1) potentially have a higher administrative burden; 2) might constrain clinician autonomy; 3) may require more time; and 4) could lead to groupthink, such that pressure to agree results in failure to think critically and premature closure (20, 80).

However, these possible disadvantages are mitigated because interprofessional, multidisciplinary management strategies can use existing resources (e.g., the institutional ethics committee) and can be tailored to the capabilities of the individual institution (81, 82). There are techniques to elicit all options and arguments, such as assigning one member to make the case for limiting life-sustaining interventions and another to make the case for continuing them. Furthermore, the possible disadvantages are outweighed by the

importance of maintaining procedural fairness and the need to protect particularly vulnerable patients.

Composition of the interprofessional, multidisciplinary committee. To ensure logistical feasibility, institutions should have flexibility in how to form the diverse interprofessional, multidisciplinary committee. For example, it may be desirable to form a subcommittee from a larger standing committee that already has the requisite interprofessional, multidisciplinary representation, such as an ethics committee. Similarly, institutional policies might assign certain processes to one or more members to accommodate local resources and to enhance efficiency. For example, the individual responding to a request for ethics consultation may also initiate convening the interprofessional, multidisciplinary committee and may delegate tasks to committee members.

Whenever possible, the interprofessional, multidisciplinary committee should include three to five members, including a physician, a nurse, and one person who is neither (e.g., a chaplain or social worker). Whenever possible, this committee should include representation from social work, the ethics committee, and the community (83, 84). The committee should not include members of the primary treatment team or its medical consultants (23). Ideally, the committee is diverse in terms of role, gender, and socioeconomic status.

Recommendation 4

Institutions should use all available information on the patient's preferences and values to guide treatment decisions. If such information is not available, the committee should collaborate with the treatment team to make decisions in the patient's best interest.

The diverse interprofessional, multidisciplinary committee and treating clinicians should use all available information on the patient's preferences and values to make the medical decision that is maximally consistent with them under the circumstances. Upon admission, most unrepresented patients do not have a clearly applicable advance directive or Provider Orders for Life-Sustaining Treatment (POLST). Regardless, the interprofessional, multidisciplinary committee should attempt to infer patients' goals, values, or wishes from evidence of the patient's

Table 5. Summary of Components of Institutional Policy

Component 1	Early identification of incapacitated and potentially unrepresented patients
Component 2	Interprofessional, multidisciplinary committee confirms that a diligent search was completed and that the patient is unrepresented
Component 3	Interprofessional, multidisciplinary committee diligently gathers information about patient's condition, goals of care, and values
Component 4	Interprofessional, multidisciplinary committee engages with clinical team to deliberate and make treatment decisions
Component 5	Expedited processes for time-pressured nonemergency decisions
Component 6	Periodic retrospective review of cases
Component 7	If applicable, follow recommended processes for potentially inappropriate treatment
Component 8	Guardianship for ongoing cases

religious, spiritual, personal, cultural, philosophical, and moral beliefs and ethics. Even though the patient is unrepresented, the interprofessional, multidisciplinary committee may still have some evidence of an unrepresented patient's preferences from an advance directive, medical record notes, previous healthcare decisions, or conversations with healthcare workers who previously cared for the patient.

When there is no reliable evidence of the patient's expressed wishes, values, or preferences, the committee should apply the best interest standard. Typically, these seven factors guide application of the best interest standard: 1) the patient's present level of physical, sensory, emotional, and cognitive functioning; 2) quality of life, life expectancy, and prognosis for recovery with and without treatment; 3) the various treatment options and the risks, side effects, and benefits of each; 4) the nature and degree of physical pain or suffering resulting from the medical condition; 5) whether the medical treatment being provided is causing or may cause pain, suffering, or serious complications; 6) the pain or suffering to the patient if the medical treatment is withdrawn or withheld; and 7) whether any particular treatment would be proportionate or disproportionate in terms of the benefits to be gained by the patient versus the burdens caused to the patient (33).

Recommendation 5

Institutions should manage decisionmaking for unrepresented patients using a fair process that comports with procedural due process such as transparency, legitimacy, and consistency.

Described below are eight proposed components of due process for a model

institutional policy (Table 5). These are broadly informed by the substitute decision-making literature, philosophical conceptions of fairness and procedural justice, and prior professional society guidelines.

1. Early identification of incapacitated and potentially unrepresented patients.

Comprehensive efforts should be made by the admitting staff and treatment team early after admission to identify a surrogate for patients lacking decision-making capacity. When it appears that the patient will be unrepresented because a surrogate cannot be found, the interprofessional, multidisciplinary committee should be consulted. This will ensure timely decision-making. If the care team or institution subsequently finds an appropriate surrogate, then that individual assumes decision-making authority.

2. The interprofessional, multidisciplinary committee convenes to confirm that a diligent search was completed and that the patient is unrepresented. Before making treatment decisions on the patient's behalf, the interprofessional, multidisciplinary committee should first confirm that the patient is, in fact, unrepresented. First, the committee should carefully document both prior efforts to determine the patient's capacity and confirm that the patient lacks capacity. Second, the committee should review prior efforts to locate potential surrogates and confirm that there is no available surrogate. After confirming that the patient is unrepresented, the committee should inform the patient (if possible) of how the committee will proceed in the decision-making process.

3. The interprofessional, multidisciplinary committee diligently gathers information about the patient's condition, goals of care, and values. The interprofessional, multidisciplinary committee should meet with the attending clinician and team and ascertain the patient's condition, medical history, social history, and prognosis. The committee should obtain a second opinion from another independent clinician with expertise in the patient's condition, addressing both the patient's prognosis and the recommended treatment plan. Consistent with Recommendations 3 and 4 above, the committee should also gather and review evidence (if any) on the patient's values and preferences, including religious and moral beliefs, and record these in the medical record. Generally, the committee should follow the instructions in an advance directive, POLST, or similar document, if available. However, such information is almost never dispositive of what care should be administered (85). The specific medical circumstances confronting a patient in the ICU and the decisions that need to be made in these circumstances are extremely difficult to anticipate.

committee engages with the clinical team to deliberate and make treatment decisions. The interprofessional, multidisciplinary committee should engage with the clinical team to deliberate and make treatment decisions. The institutional policy should establish whether the committee is serving as a surrogate in a shared decisionmaking model with the treatment team (making the treatment decision) or acting in an advisory and oversight role (providing recommendations and ensuring soundness of deliberations). Either way, the committee should explain the basis for its decisions or recommendations, especially how they are consistent with the patient's values and priorities, if they are known. If such information is not available, the committee should explain how the decision promotes the patient's best interest by maximizing

4. The interprofessional, multidisciplinary

The committee should not approve any treatment decision on the basis of the patient's age, race, color, religion, ancestry, national origin, disability, gender, gender identity, gender expression, sexual orientation, or ability to pay, unless such a factor is clearly clinically relevant or is pertinent to the patient's known values,

benefit and minimizing burden.

such as a Jehovah's Witnesses patient's wish not to receive blood products. The committee should always advocate for the provision of appropriate pain relief and palliative care.

- 5. Expedited processes for time-pressured nonemergency decisions. When time pressures (such as a rapidly deteriorating clinical condition) make it infeasible to convene a diverse interprofessional, multidisciplinary committee, clinicians should endeavor to achieve as much procedural oversight as the clinical situation allows. Whenever possible, clinicians should obtain confirmation from a clinical ethics consultant or from an independent clinician that an expedited process is necessary. In situations in which decisions must be made so quickly that no procedural oversight is possible, there should be retrospective review. Clinicians should, to the extent possible, not allow situations to become time pressured. It is ethically "troublesome" to wait "until the patient's medical condition worsens into an emergency so consent to treat is implied" (8).
- 6. Periodic retrospective review of cases. A mechanism for periodic retrospective review of decisions for unrepresented patients should be a component of an institutional policy. A regular review process, such as a closed session of an unrepresented morbidity and mortality conference, helps to achieve efficient and consistent management of cases and may identify areas for improvement in institutional practices (86).
- 7. If applicable, follow recommended processes for potentially inappropriate treatment. If the care team believes that the interprofessional, multidisciplinary

committee is requesting interventions that are futile or potentially inappropriate, they should refer to the 2015 multiorganization consensus statement on responding to requests for futile or potentially inappropriate interventions in the ICU (86). In these cases, a formal ethics consultation and review by the hospital's ethics committee should be initiated. Both to ensure due diligence and to avoid role confusion, the interprofessional, multidisciplinary committee in this process should not be the same committee promoting procedural fairness on behalf of the unrepresented patient. In cases of persistent disagreement, if feasible on the basis of local laws and resources, the institution should consider initiating the appropriate processes in its jurisdiction to obtain a legal guardian or conservator.

8. Guardianship for ongoing cases. A goal of this document is to identify a process by which clinicians can provide nonemergent medical care for an unrepresented patient without a surrogate's consent. The number and complexity of decisions for unrepresented patients may increase as these patients become sicker. However, sometimes the care team expects an unrepresented patient to remain incapacitated with ongoing healthcare needs for a considerable length of time. In these cases, if feasible on the basis of local laws and resources, the institution should consider initiating the appropriate processes in its jurisdiction to obtain a legal guardian or conservator (11).

Recommendation 6 Institutions should employ this fair process even when state law authorizes procedures with less oversight.

Some state laws authorize clinicians to make treatment decisions on behalf of unrepresented patients with little or no oversight (Table 2) (87-91). Yet, because of the vulnerability of unrepresented patients, hospitals within these jurisdictions should still use a diverse interprofessional, multidisciplinary committee. In these states, attending clinicians may be the officially recognized decision-makers, but they should still consult with an interprofessional, multidisciplinary committee and follow the above due process and institutional policy. To reconcile this policy statement with the law in these states, the committee may function in an advisory and consultative capacity rather than in a decision-making capacity.

Conclusions

Unrepresented patients in the ICU are particularly vulnerable. Consequently, treatment decisions on their behalf should be evaluated carefully. This policy statement is designed to help clinicians and hospital administrators design fair and practical procedures for making treatment decisions on behalf of unrepresented patients in the ICU setting.

This official policy statement was prepared by an *ad hoc* subcommittee of the American Thoracic Society and the American Geriatrics Society.

Members of the subcommittee are as follows:

Thaddeus M. Pope, J.D., Ph.D. (*Co-Chair*)¹ Douglas B. White, M.D., M.A.S. (*Co-Chair*)² Joshua Bennett, J.D.³ Shannon S. Carson, M.D.³ Lynette Cederquist, M.D.⁴ Andrew B. Cohen, M.D., D.Phil.⁵ Erin S. DeMartino, M.D.⁶ David M. Godfrey, J.D.⁷ Paula Goodman-Crews, M.S.W., L.C.S.W.⁸ Marshall B. Kapp, J.D., M.P.H.⁹ Bernard Lo, M.D.¹⁰ David C. Magnus, Ph.D.¹¹ Lynn F. Reinke, Ph.D.¹²

Jamie L. Shirley, Ph.D., R.N.¹³
Mark D. Siegel, M.D.⁵
Renee D. Stapleton, M.D., Ph.D.¹⁴
Rebecca L. Sudore, M.D.¹⁵
Anita J. Tarzian, Ph.D., R.N.¹⁶
J. Daryl Thornton, M.D., M.P.H.¹⁷
Mark R. Wicclair, Ph.D.¹⁸
Eric W. Widera, M.D.¹⁵

¹Mitchell Hamline School of Law, St. Paul, Minnesota; ²University of Pittsburgh, Pittsburgh, Pennsylvania; ³University of North Carolina, Chapel Hill, North Carolina; ⁴University of California San Diego Health, San Diego, California; ⁵Yale University, New Haven, Connecticut; ⁶Mayo Clinic, Rochester, Minnesota; ⁷American Bar Association, Washington, DC; ⁸Kaiser Permanente, San Diego, California; ⁹Florida State University, Tallahassee, Florida; ¹⁰Greenwall Foundation, New York, New York; ¹¹Stanford University, Stanford, California; ¹²Veterans Affairs Puget Sound Health Care System, Seattle, Washington; ¹³University of Washington, Seattle, Washington; ¹⁴University of Vermont, Burlington, Vermont; ¹⁵University of California, San Francisco, San Francisco, California; ¹⁶University of Maryland, Baltimore, Maryland; ¹⁷MetroHealth, Cleveland, Ohio; and ¹⁸West Virginia University, Morgantown, West Virginia

Author Disclosures: D.B.W. received author royalties from UpToDate. S.S.C. received research support from BioMarck Pharmaceuticals, Triangle Pharmaceuticals, and United Pharmaceuticals. M.D.S. served as a consultant for Siemens Healthcare; and

AMERICAN THORACIC SOCIETY DOCUMENTS

received author royalties from UpToDate. R.D.S. served on a data and safety monitoring board for Lyric Pharmaceutical. E.W.W. is

a board member of the American Academy of Hospice and Palliative Medicine. T.M.P., J.B., L.C., A.B.C., E.S.D., D.M.G., P.G.-C., M.B.K., B.L., D.C.M., L.F.R., J.L.S., R.L.S., A.J.T., J.D.T., and M.R.W. reported no relationships with relevant commercial interests.

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