



Published in final edited form as:

Lancet Respir Med. 2019 July ; 7(7): 626–638. doi:10.1016/S2213-2600(19)30087-6.

Aligning use of intensive care with patient values in the USA: past, present, and future

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Abstract

For more than three decades, both medical professionals and the public have worried that many patients receive non-beneficial care in US intensive care units during their final months of life. Some of these patients wish to avoid severe cognitive and physical impairments, and protracted deaths in the hospital setting. Recognising when intensive care will not restore a person's health, and helping patients and families embrace goals related to symptom relief, interpersonal connection, or spiritual fulfilment are central challenges of critical care practice in the USA. We review trials from the past decade of interventions designed to address these challenges, and present reasons why evaluating, comparing, and implementing these interventions have been difficult. Careful scrutiny of the design and interpretation of past trials can show why improving goal concordant care has been so elusive, and suggest new directions for the next generation of research.

Introduction

For at least 30 years, medical professionals have worried that too many US citizens receive non-beneficial treatments in intensive care units (ICUs) at the end of life.¹ The citizens' fear

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AET wrote the first draft. All authors reviewed and edited the manuscript.

Declaration of interests

We declare no competing interests.

This is the third in a **Series** of three papers about improving the use of critical care for Americans with terminal illness

See **Online** for appendix

that they will be unable to avoid such treatment helped to fuel the Patient Self Determination Act of 1990,² the legally-recognised physician orders that can be carried around by citizens as protection against unwanted treatment (ie, the Physician Orders for Life-Sustaining Treatment document and the Maryland Medical Order for Life-Sustaining Treatment document),³ and access to physician aid in dying.⁴ Despite these concerns and efforts, the proportion of older Americans (>65 years) who were admitted to an ICU during their last month of life increased steadily from 24% to 29% between 2000 and 2009,⁵ and has not changed substantially since.⁶ By comparison, only 10% of Canadians and 4% of Germans are admitted to an ICU during the last month of life.⁷ This difference is especially pronounced in older people. In 2001, 32% of Americans aged 85 years or older who died in hospital were treated in a medical ICU during their terminal hospitalisation, compared with 2% in England.⁸

Most people agree that avoiding burdensome and invasive treatments is emotionally preferable to withdrawing them.^{9,10} But there will always be patients for whom the benefit of life support is uncertain, and a trial of intensive care is appropriate. For these patients, the question becomes how long ICU care should continue if the patient is not recovering. The conflicting desires to both try treatments with uncertain benefit while simultaneously avoiding a medicalised death seem inherent to being an American. A study of first and second generation immigrants to the USA with terminal cancer found that those with higher levels of US acculturation were more likely to receive chemotherapy, more likely to participate in trials, and also more likely to report that they did not want to die in an ICU, than those with lower levels of US acculturation.¹¹ Such patients who wish to try therapies of uncertain benefit and also avoid a protracted death, rely on physicians to point out when continuing treatment might preclude their ability to live, or to die, in a way they value. Recognising these pivotal decision points, and helping patients and families who are not benefitting from ICU care embrace achievable goals related to symptom relief or spiritual fulfilment, is arguably one of the most challenging procedures in critical care.¹²

In this Series paper, we describe research centred on ensuring that adult patients admitted to ICUs in the USA receive care consistent with their values and goals. We propose that these complex interventions designed to promote behavioural change present challenges to evaluating and comparing their effectiveness. We highlight both systems and cultural factors that affect their implementation. Finally, we discuss ideas for aligning ICU care with patient goals that are yet to be tested but might herald new and innovative directions for the field.

The legacy of the SUPPORT trial

The landmark SUPPORT trial¹³ published in 1995 was a pioneering study in the field. In their 2-year, prospective cohort study enrolling more than 8000 seriously ill hospitalised patients, the SUPPORT trial investigators found that providing physicians with prognostic estimates about short-term and long-term outcomes had no effect on the proportion of patients asked about their preference for cardiopulmonary resuscitation, length of ICU stay, incidence or timing of Do Not Resuscitate orders, or the use of mechanical ventilation before death. Although disheartening, the SUPPORT trial allowed the field to reject the hypothesis that dying patients are over-treated because intensivists are unaware of their

prognoses. Since the SUPPORT trial, the predominant hypothesis has been that the modifiable variable causing over treatment of patients in the ICU is infrequent or poor-quality communication between physicians working in the ICU and patient families. More recently, interventions to foster goal-concordant ICU care¹⁴ have generally sought to increase the frequency and quality of communication between physicians and families during multidisciplinary ICU family meetings. Our search for peer-reviewed research published in the past decade that evaluated interventions to improve communication between US physicians and adult patients in the ICU or their families published in the past decade illustrates the diverse ways that this hypothesis has been tested.

Selected studies of communication interventions using pre-post designs

Pre-post study designs have been useful for testing approaches to improving communication with families of patients in the ICU (appendix). The study by Mosenthal and colleagues¹⁵ provided no new training for the ICU's existing staff. Instead, new personnel including palliative care physicians, nurses, and bereavement counsellors were integrated into the unit workflow. These personnel assessed all patients within 24 h of ICU admission during the intervention period and asked the patient's attending physician and nurse about the patient's most probable outcome using a Likert scale with 1 meaning death and 5 meaning independent functional recovery. Regardless of the attending physician's response, a family meeting led by the attending physician was encouraged within 72 h. By contrast, the approach taken by Hatler and colleagues¹⁶ provided existing ICU staff with 4 h of training, introduced no new personnel, and focused only on patients with ICU stays of 7 days or longer, or who had been mechanically ventilated for 96 h or more. Finally, a 2010 pre-post study by Daly and colleagues¹⁷ provided both formal training for existing staff and incorporated a dedicated advance practice nurse into each participating ICU. These advance practice nurses made no attempt to alter physician communication styles or direct decisions, but worked to schedule multidisciplinary family meetings that included the attending physician within 5 days of ICU admission for all patients with 72 h or more of mechanical ventilation.

Despite their different approaches, these three interventions affected patient care similarly. None of them resulted in significant changes in ICU or hospital mortality or in the proportion of patients with Do Not Resuscitate orders. However, the mean length of hospital stay decreased significantly from 21 days to 15 days in Hatler's cohort,¹⁶ and was reduced by half among decedents in Mosenthal's cohort¹⁵ from 14 days to 7 days. Interestingly, the effect on patients in the Daly cohort¹⁷ appeared to be mediated by ICU type. For example, the proportion of patients in surgical ICUs receiving a tracheostomy before death was stable, but among 50 decedents in medical ICUs, tracheostomy dropped from 6 (55%) of 11 patients to 5 (13%) of 38 patients. Process measures provided relatively few hints about the mechanisms driving these changes. However, Mosenthal and colleagues¹⁵ reported that whereas the proportion of patients with a family meeting did not change (62% before vs 60% after), goals of care discussions during rounds increased from 32 (4%) to 313 (36%), suggesting that the content of conversations within the clinical team, rather than the incidence of contact between clinicians and families, might have driven the observed changes.

Randomised trials of ICU communication interventions

At least four multi-site trials of communication interventions involving family meetings were done in US adult ICUs between 2008 and 2018 (table 1). Trial designs and a description of the interventions are summarised in the appendix. Inclusion criteria varied, but three trials^{19–21} targeted the families of mechanically ventilated patients who received at least 24 h of ICU care and had poor long-term prognoses, whereas the trial from 2011 by Curtis and colleagues¹⁸ measured outcomes among families of patients who died during an ICU stay and those who died within 30 h of transfer to another hospital location.

As with the earlier pre-post studies,^{15–17} the personnel used in the trial interventions varied. The 2011 trial by Curtis and colleagues¹⁸ introduced no new personnel, a palliative care physician and nurse practitioner led family meetings in the 2016 trial by Carson and colleagues,²⁰ and specially trained ICU nurses and social workers facilitated meetings led by ICU attendings in the 2016 trial by Curtis and colleagues¹⁹ and in the trial by White and colleagues.²¹ Additional training for existing ICU clinicians ranged from none^{19,20} to multiple in-person education sessions in each ICU.²¹ The timing and frequency of interactions with family members also differed across studies. Mechanically ventilated patients with a sequential organ failure assessment score of 6 or higher, or at least a 30% chance of hospital mortality, were approached by communication facilitators as early as 24 h after admission in one trial.¹⁹ Whereas patients did not become eligible for an intervention meeting until they had been mechanically ventilated for at least 7 days in another.²⁰ Although fidelity to the intervention protocol was unclear in some cases, the protocol in 2018 by White and colleagues²¹ included the largest planned dose of contact, consisting of families meeting with interventionists daily, and participating in a family meeting led by the attending physician within 48 h of enrolment.

Analysis and results of these four trials are presented in the appendix. All studies enrolled family members of adult patients in the ICU with total enrolment ranging from 268 family members to 1106 family members, and cohort retention ranging from 46% (396 assessed out of 822 enrolled)¹⁸ to 73% (809 assessed out of 1106 enrolled).²¹ The 2011 trial by Curtis and colleagues¹⁸ used the validated Quality of Death and Dying scale^{22,23} as the primary outcome, whereas the other trials used validated instruments for assessing mental health symptoms. Enrolled families were assessed between 4 weeks and 6 months after ICU discharge. All trials estimated the effect of being randomised to the intervention group (ie, intention-to-treat analysis) using multivariable generalised linear regression.

None of the trials reported a significant change in reports by family members of symptoms of depression, anxiety, or post-traumatic stress except for less frequent depression symptoms measured at 6 months in the 2016 trial by Curtis and colleagues,¹⁹ and an increase in post-traumatic stress symptoms in the 2016 trial by Carson and colleagues.²⁰ The trial by White and colleagues²¹ was the only intervention with a statistically significant effect on hospital mortality which rose from 264 (30%) of 873 patients in the control group to 208 (38%) of 547 patients in the intervention group. Interventions integrating trained interventionists into daily work flows changed the length of stay significantly. The 2016 trial by Curtis and colleagues¹⁹ and the 2018 trial by White and colleagues²¹ both observed significant

decreases in mean hospital length of stay for all patients; ICU length of stay among patients who died during an ICU stay dropped precipitously from 29 days to 8 days in the trial by Curtis and colleagues,¹⁹ and from 7 days to 4 days in the trial by White and colleagues.²¹ However, changes in mortality were not consistent. The intervention group had lower mortality than the control group in the trial by Curtis and colleagues,¹⁹ but higher mortality than the control group in the trial by White and colleagues.²¹

The consistent association between early, structured communication by the ICU team and decreased length of stay in these trials is unsurprising. Purposeful, structured communication with critically ill patients and their families has been associated with decreased length of stay for at least 15 years.²⁴ But how this association is interpreted is contentious. Sceptics worry that decreased length of stay, particularly paired with higher in-hospital mortality, is a sign that clinicians in the intervention group of the trial inappropriately pressured families into withholding or withdrawing life-support from patients who would have preferred to continue treatment. Supporters point to the same data as evidence that when clinicians disclose prognosis and inform patients and families that they have the option of avoiding or stopping life-support technology early in an ICU stay, a substantial portion freely choose to do so, even when that means dying sooner. Currently, interpreting the association between early communication and length of stay serves as a test that shows much about the viewer's beliefs about doctors and the citizenry. Qualitative work might help to clarify which of these interpretations reflect reality.

Communication interventions as behaviour change campaigns

The different interventions evaluated in the past decade reflect the tools at hospitals' disposal when advocating for changes in practice (figure 1). The 2011 trial by Curtis and colleagues¹⁸ using grand rounds presentations, videos that are easily incorporated into online teaching modules, and educational pamphlets, is emblematic of low-cost, quality improvement campaigns commonly used across large health systems. Such campaigns assume the primary barrier to change is insufficient awareness or familiarity,²⁵ and provide information or training but no new personnel. By contrast, the 2016 trial by Carson and colleagues²⁰ encapsulates the way ICUs in hospitals with a new palliative care service sometimes operate. In this trial, palliative care providers were people employed outside of the core ICU team who met with families once or twice about patients who were not recovering despite more than a week of ICU care. Importantly, ICU attendings participated in only 10 (9%) of 116 family meetings led by these palliative care specialists. Neither the awareness-raising campaign nor the late introduction of an outside team had any significant effect on patient outcomes, and post-traumatic stress symptoms were marginally worse among families randomly assigned to a palliative care-led family meeting.

By contrast, the trials by Mosenthal,¹⁵ Curtis,¹⁹ and White,²¹ and their respective colleagues integrated personnel with new roles and additional training into the existing ICU team. In the trial by White and colleagues, interventionists were nurses who were hand-selected by the ICU director, thus ensuring that they were familiar faces trusted by the ICU leadership. In each of these studies, interventionists were responsible for preparing families to speak with physicians, and for scheduling multidisciplinary family meetings led by ICU attendings. In

both trials,^{19,21} the initial contact between interventionist and family often happened within 24 h of admission, and a first family meeting occurred within 2–3 days of eligibility. The interventionists did not provide the attendings with new information or attempt to influence the options presented to families. Rather, they assumed that the attendings possessed the knowledge and attitudes required for high-quality communication and removed external family and environmental barriers to meetings (ie, coordinated everyone's schedules to make both time and space for meetings).²⁵

Challenges in the design and interpretation of ICU communication studies

Designing and interpreting evaluations of communication interventions in the ICU is difficult for at least six reasons (panel). First, most critically ill patients are too ill to participate in a research study. Some patients are too ill to complete surveys at discharge or follow-up, and a substantial proportion die before hospital discharge. These circumstances mean that even the most rigorous study doesn't have adequate feedback from the most important person potentially affected by the intervention, and instead rely on reports from their family members or surrogate decision-maker. Second, there is no clear consensus on a target population. Previous studies have attempted to enrol patients at high risk of death or long-term functional impairment by limiting enrolment to patients with a minimum duration of mechanical ventilation. This strategy excludes patients with short but potentially traumatic ICU stays. Other studies have enrolled patients whom attendings believe have a risk of death of higher than 30%.^{19,21} This approach ensures that attending physicians agree that a directed effort at high-quality communication is appropriate for the families in the study. However, physician predictions about in-hospital mortality are deeply imperfect.^{26,27} Moreover, this approach re-enforces the idea that structured communication with families is only necessary if patients are at high risk of death despite a substantial body of research showing that patients who survive after a stay in the ICU often experience new, long-lasting impairments^{28,29} and their family members are at increased risk of long-term depression.³⁰ Third, enrolling a representative sample of family members can be challenging. Laws about who is authorised to make medical decisions for an incapacitated patient vary greatly across the 50 states in the USA.³¹ To further complicate matters, clinicians often speak to whichever family member is present at the bedside when consent or input is desired. To reflect this reality, most trials enrol English-speaking family members who are present and engaged in clinical decision-making regardless of their legal authority. Study cohorts assembled using these criteria are representative of the families of patients in the ICU who are available for family meetings; however, the patients of enrolled families might not be representative of the ICU's patient population. Daily attempts to enrol family members of 284 eligible patients in one ICU found that only 38% of the eligible patients had an enrolled family member after 7 days of screening, despite 92% of approached families agreeing to participate.³² The patients with an enrolled family member were significantly more likely to be white and to live in a wealthy neighbourhood. Poorer patients were less likely to have a family member at their bedside. Although not well studied, this setting might be because poorer families are less likely to have access to transportation and the ability to miss work without risking wage or job loss. In a past trial,³³ families of patients in the ICU who received palliative care were also more likely to respond to follow-up surveys, introducing

response bias. Most studies do not enrol families with limited English proficiency. A study from 2018 of decedents in one hospital found that it took an average of 19 days longer for patients with limited English proficiency to transition to care focused on comfort compared with English-speaking patients after adjusting for differences in education and insurance status.³⁴ These challenges make it difficult to forecast how communication interventions might affect care in ICUs serving diverse or disadvantaged populations. Fourth, randomisation levels vary and blinding is nearly impossible in clinical trials of communication interventions. Investigators have thus far randomly assigned patients in the ICU,¹⁹ patient–family dyads,²⁰ ICUs,²¹ and entire hospitals.¹⁸ Random assignment of individual patients is imperfect because most interventions seek to change an aspect of physician behaviour (eg, if and when physicians call family meetings, what families are told during meetings, etc). Once learned or adopted, such behaviours are difficult to stop when interacting with families randomised to usual care. Random assignment of clinicians is possible, but patients in the ICU with more than a few days stay are rarely treated by a single clinician, which prevents inferences about the intervention's effect on patient outcomes. Unlike exposure to a pill whose effects can be isolated, attitudes and behaviours tend to leak within a population. Cluster randomised trials, including stepped-wedge trials, are an appropriate design choice under these conditions.³⁵ However, the trade-off inherent in a cluster-randomised design is efficiency. Because patients within a cluster are correlated, they each contribute less unique information. This correlation within a cluster decreases the effective sample size, the precision of treatment effect estimates, and the power of the trial.³⁶ Fifth, ICU communication initiatives are complex interventions with interacting components targeting the behaviours of both clinicians and families.³⁷ Embedding process evaluation within trials of complex interventions, as recommended by the UK Medical Research Council, can provide insight into causal mechanisms, reproducibility, implementation fidelity, and contextual factors associated with outcomes.³⁸ When conversations are the crux of an intervention, knowing what was said, what was understood, when, and by whom, is vital to the process evaluation. For now, there is no validated way to quantify the timing and intensity of communication that occurs between ICU proxies and the team. To carry forward the pill analogy previously mentioned, investigators are minimally able to determine the number of milligrams administered (ie, frequency of meetings and basic content of discussion) but are unable to determine the bloodstream concentration of the drug (ie, how the communication was perceived by the surrogate decision-maker). As a result, families of patients with similar lengths of stay can receive radically different doses of communication (figure 2); and, more problematic, investigators have few measures for dose or uptake.

Recording family meetings can help to address this problem, but many interactions with ICU proxies take place outside formal meetings, permission to record family meetings is tricky to obtain, and recordings do not always capture the emotional temperature of a meeting. Although family meetings have successfully been audio recorded in past studies,^{39,40} the families and clinicians who consent to recordings are likely to be different from those who do not, and the act of recording introduces the Hawthorne effect by which study participants behave differently when they are aware of being observed or recorded.⁴¹ As a result, we usually do not know what transpires in family meetings or which components of communication interventions were most effective. For example, did the length of stay

decrease in the 2018 trial by White and colleagues²¹ because family meetings were scheduled sooner, or because physicians presented different treatment options, or because families asked different questions as a result of the question prompt lists. Without data from the room where it happens, we do not know.

Finally, the greatest challenge in studies of communication interventions is selecting an appropriate primary outcome. The ideal intervention would prevent both undertreatment and overtreatment, decrease the moral distress of clinicians, improve the mental health of family members, and require minimal time, effort, and money. That is a difficult task that cannot be assessed using a single outcome measure. Although patients should be the first priority, the field does not have a validated method for assessing whether patients are receiving goal-concordant care.^{14,42} Patient goals, such as being well enough to live at home, living long enough to witness a birth or wedding, or being comfortable, often change over the course of a life and the course of an ICU stay, and are rarely recorded in the medical record. And when a patient's goals are known, agreement among intensivists about whether treatments could help to achieve them is only moderate.⁴³ For these reasons, patient-centred outcomes in trials of communication interventions have usually been limited to mortality and length of stay.

Communication interventions have resulted in decreased length of stay without a substantial change in hospital mortality across multiple studies, which supports the hypothesis that poor communication contributes to over-treatment. It also suggests that holding high-quality family meetings earlier during an ICU stay speeds up a process whose outcome is foreordained. This interpretation has been comforting for clinicians who fear that telling patients and families about the option of withdrawing life-support will result in avoidable deaths. However, this interpretation is challenged by the 2018 trial by White and colleagues²¹ in which families randomly assigned to the intervention perceived their loved ones as receiving more patient-centred care, their doctors as more skilled communicators, and there was a significant 8 percentage points increase in hospital mortality.²¹ Crucially, the trial also found no significant difference in 6-month mortality or the proportion of patients living independently in their homes 6 months later.²¹ One interpretation is that the intervention allowed families who believed their loved one would prefer dying in the hospital to spending their last weeks or months in a residential facility to voice that opinion, and influence treatment decisions that might have resulted in an earlier death but not necessarily a worse or avoidable one.

Given the difficulty of assessing patient outcomes, communication trials have used the mental health symptoms of surrogate decision-makers of patients in the ICU 3–6 months after discharge of the patient as their primary outcome. Inherent in this decision is a belief that the long-lasting anxiety, depression, and post-traumatic stress experienced by some surrogate decision-makers of patients in the ICU⁴⁴ regardless of whether the patient survives, stems from insufficient emotional support during the surrogate decision-making process. There is evidence suggesting that this hypothesis might be true. For example, a secondary analysis of more than 300 surrogate decision-makers found only high baseline anxiety and depression, and patient unresponsiveness on day 10 of mechanical ventilation were associated with post-traumatic stress symptoms in surrogate decision-makers 3 months

later.⁴⁵ Day 10 of mechanical ventilation is a common clinical crossroad. One hypothesis is that surrogate decision-makers of unresponsive patients on day 10 were asked to choose between a tracheostomy and withdrawing ventilator support, and developed post-traumatic stress symptoms as a result of this decision. But there is also reason to think that one potentially modifiable cause of the mental health symptoms of families of patients in the ICU is not the burden of surrogate decision-making, but their lack of control over their loved one's medical care. In qualitative interviews, surrogate decision-makers have described their decision to limit or stop life-support as allowing them to regain a sense of power and control that eased the feelings of helplessness that they experienced while witnessing their loved one's ICU care.⁴⁶ Feelings of helplessness and frustration are not uncommon. In a survey of 1495 surrogate decision-makers of patients in the ICU, 856 (57%) reported they had poor control over the care their family member was receiving.⁴⁷ Informing families that they can direct care to be focused on comfort, longevity, or some other goal early in the course of an ICU stay, rather than after the clinical team feels certain that the patient is unlikely to recover, might help to alleviate or shorten this period of perceived helplessness. Given the conflicting evidence on how surrogate decision-makers respond to their decision-making authority (ie, does it cause psychological harm, or does it protect them against feelings of helplessness?), assessing what role family members wish to have in the decision-making and responding accordingly is essential for physicians. This task means both ceding control when surrogate decision-makers prefer choosing independently between acceptable treatment options, and assuming responsibility when surrogate decision-makers ask physicians to make difficult decisions as described in the policy statements of American critical care societies.⁴⁸

Interventions tested thus far have not had a substantial effect on the mental health outcomes of surrogate decision-makers for patients in the ICU. Trials have also struggled with loss at follow-up. This trend is not surprising given that attrition rates are normally about 25% in clinical trials evaluating treatments for post-traumatic stress syndrome.^{49,50} Because avoidance is a hallmark of this disorder, surrogate decision-makers with post-traumatic stress symptoms might be more likely to drop out of a study that asks them to recall a traumatic experience, thereby raising the possibility of selection bias.⁵¹ Finally, it is unclear what degree of depression and anxiety is appropriate or normal among surrogate decision-makers of patients in the ICU. Given that a substantial proportion of families are bereaved, and families of patients surviving an ICU stay often face decreased employment,⁵² new caregiving demands, and financial stress,⁵³ some increase in anxiety and depression symptoms might be expected in this population. For all these reasons, mental health symptoms of a surrogate decision-maker are not ideal outcomes for ICU communication trials. However, until there is a strong, validated, alternative metric, these outcomes will probably still be used.

Obstacles to implementing goal-concordant ICU care

Clinical practice patterns in ICUs are shaped by cultural norms. Both US geographical regions,⁵⁴ and institutions^{55–58} vary widely in their approach to caring for patients at the end of life. Research informed by behavioural psychology and sociology suggests cultural and contextual influences might help to explain this variety. For example, the term clinical

momentum⁵⁹ has been used to describe the combination of recognition-primed decision-making,⁶⁰ the cascade effect,⁶¹ and sunk cost effects.^{62,63} Clinical momentum posits that both patients and clinicians view medicine's role as restoring normal physiological function, even when changes in physiology are a normal part of ageing and dying. Clinicians are trained (or primed) to recognise such physiological deviations and rewarded for quickly matching them to diagnostic tests or treatments. These tests and treatments in turn can cause complications or pain, which then trigger further treatments, setting off a cascade of interventions, each of which is an irretrievable investment of time, effort, and money. Thus, a perceived obligation to repair a physiological abnormality can set a process in motion that continues without consideration for long-term consequences.

Although the long-term consequences of treatment might not be the primary consideration of most clinicians in the ICU, they are essential to patients. Older patients (>60 years) with cancer, congestive heart failure, and chronic obstructive pulmonary disease prefer treatments with high potential for an adverse outcome of death to a high potential for functional or cognitive impairment.⁶⁴ Yet, these patients are routinely admitted to ICUs even though surviving an ICU stay frequently results in new or worsening physical^{28,65} or cognitive^{29,66} impairment. Scarce knowledge among older patients and their families about the long-term outcomes of critical illness contributes to this incongruous decision. In audio-recorded family meetings, intensivists discussed the long-term quality of life in only 52 (45%) of 116 meetings,⁶⁷ and long-term physical and cognitive function in 9 (12%) of 71 meetings,⁶⁸ with most meetings focused instead on the patient's current condition and descriptions of diagnostic or life-prolonging treatment options.⁶⁹ Among the factors making intensivists hesitant to discuss long-term outcomes are scarcity of contact with patients beyond ICU discharge, discomfort expressing uncertainty,⁷⁰ and even the belief among some clinicians that long-term outcomes should not influence decisions.⁷¹

American culture, politics, and history also have a role in the cause of clinician discomfort in discussing long-term prognosis and advance care planning. The medical community's history of discrimination against racial minorities, including segregated health-care facilities and unethical clinical research,^{72,73} has ongoing consequences. Black and Hispanic citizens report greater distrust in health-care professionals than do white Americans.⁷⁴ American intensivists, most of whom are white or Asian⁷⁵ and aware of this history, might spend days trying to build trust with families in minority groups before they feel comfortable saying anything that could be interpreted as advocating for limiting treatment. Also, in an attempt to erode support for the Patient Protection and Affordable Care Act, which was signed into law in 2010, many Americans were misled to believe that the law would result in doctors or politicians denying treatment to older patients on the basis of cost.⁷⁶ In this distrustful milieu, it is understandable that some intensivists are unnerved when disclosing a poor long-term prognosis.

The fact that intensivists are nervous about disclosing long-term prognosis does not mean that providing patients and their surrogate decision-makers with information about long-term outcomes and encouraging them to state their opinions will necessarily change current practice. Physicians rarely elicit information about patient treatment preferences,⁷⁷ and silence from well informed patients and surrogate decision-makers cannot be interpreted to

mean they are receiving appropriate care. This behaviour is because families fear that expressing a preference for less aggressive treatment, or even pointing out a potential mistake, will get them labelled a troublemaker or a difficult patient.^{78–80} It is also naive to assume that when patients and surrogate decision-makers do speak up, their preferences affect care. On the contrary, preferences and values voiced by patients and surrogate decision-makers have no effect on when physicians permit patients to transition to end-of-life care, as shown in both clinical vignettes and longitudinal cohort studies.^{81,82} In this setting, telling patients and surrogate decision-makers that they can prevent overtreatment by simply speaking about their values in family meetings is disingenuous. Relying on surrogate decision-makers to prevent overtreatment or slow clinical momentum is also not a solution because up to 27% of patients in some ICUs do not have any surrogate decision-maker.^{83,84}

When physicians present the option of care focused on comfort, this presentation is strongly influenced by the ethos of their specialties.^{85,86} The most well documented example is in surgery, in which many surgeons believe that they obtain permission to dictate the duration of post-operative ICU care on the basis of informal preoperative discussions.^{87–89} Reporting metrics, such as 1-year survival after organ transplant, can also motivate physicians' timing of discussions about end-of-life care.^{90,91} These beliefs and metrics are deeply entrenched aspects of practice for many specialists that are improbable to change without purposeful effort from within these subspecialties.

Nurses, who occupy an intermediary position in ICU communication, cannot prevent overtreatment alone. Because nurses are omnipresent at the bedside, patients in the ICU and their families frequently share their goals, concerns, and questions with them. Nurses perceive relaying these statements to physicians and advocating for appropriate care on behalf of patients as essential to their professional role.⁹² However, nurses working in the ICU are generally not authorised to discuss prognosis or palliative care with patients and families.⁹³ So although nurses working in the ICU might understand the concerns and motivations of both patients and physicians, they are generally intercessors empowered to move information in only one direction.

Finally, surveys suggest ICU providers in the USA often continue life-support even when they perceive it to be inappropriate.⁹⁴ The umbrella term of potentially inappropriate is used to encompass both requested treatments that are not expected to help with achieving a patient's goal, and treatments that will help to achieve a goal of questionable value to the medical team, such as being alive with end-stage dementia and multiple organ failure. In 2015, critical care professional societies endorsed a process-based approach to resolving disputes in these situations.⁹⁵ This seven-step process involves enlisting consultants skilled in mediation, obtaining second opinions, involving an interdisciplinary hospital committee in conflict resolution, and giving patients the opportunity to transfer to another hospital or engage the legal system. To be effective, hospitals must adopt the policy, support clinicians who initiate the process, and maintain an interdisciplinary committee who can respond promptly and efficiently to requests for mediation. If clinicians perceive the dispute-resolution process to be more time-consuming and burdensome than simply continuing to provide inappropriate care, it is unlikely to be invoked. The extent to which this process is used is unknown, and its effect on patient care is unclear.

Recommendations for future research

Investigators will continue to trial interventions in this field, particularly given the National Heart, Lung, and Blood Institute's programme announcement in January, 2019, supporting research that uses practical approaches to increase the uptake of shared decision-making, including in the ICU setting (programme announcement number PA-19-166).⁹⁶ We have six recommendations that are likely to be applicable to many of the studies funded as a result. First, recognise that most initiatives in this field are very complex behavioural interventions and collect as much data as possible on process evaluation and implementation fidelity. Second, eligibility for interventions designed to ensure that patients receive appropriate, goal-concordant care should not be defined by whether clinicians expect the patient to die during the admission. Defining eligibility this way re-enforces the misconception that engaging families in shared decision-making is only necessary when the clinical team believes the patient is actively dying. This criterion also excludes a considerable subgroup of dying patients, given physicians' limited ability to prognosticate survival to discharge, particularly early in an ICU stay.²⁶ Third, always assess the representativeness of the enrolled study sample and how loss to follow-up might have biased effect estimates in longitudinal cohort studies. Fourth, seek to measure both the dose of the intervention received, and the effect of that dose on patient and family perceptions. Fifth, treat the clinician leading family meetings as a confounding variable. The risk-adjusted mortality of mechanically ventilated patients varies according to which physician cares for them and this variability is not explained by a physician's previous experience managing mechanically ventilated patients.⁹⁷ Given that clinicians are unlikely to be balanced across treatment groups, this imbalance makes the clinician a confounding variable in most causal models. Finally, consider collecting data on how the multi-society process-based approach to dispute resolution⁹⁵ is being used.

Future directions and potential innovations

Efforts to match the care that patients receive in ICUs with the care they desire motivates multiple trials currently underway (table 2). A follow-up to the 2016 trial by Curtis and colleagues¹⁹ of communication facilitators will focus on engaging patients and surrogate decision-makers earlier during their ICU stay and continuing to support them across care transitions for months after ICU discharge (). A follow-up to the 2018 trial by White and colleagues²¹ is also planned () and will include audio-recordings of interventionist encounters to assess fidelity.⁹⁸ Both of these trials will use mental health outcomes of surrogate decision makers as primary outcomes.

Teams are also doing large pragmatic trials to test whether small changes to the clinical decision-making environment, or so-called nudges, can improve ICU care.⁹⁹ The Randomized Evaluation of Default Access to Palliative Services (REDAPS) study aims to enrol between 12 000 and 15 000 patients aged 65 years or older with a diagnosis of advanced chronic obstructive pulmonary disease, end-stage renal disease, or dementia and a hospital stay of at least 72 h.¹⁰⁰ A default order for a palliative care consult will be created for all patients during the intervention phase of the trial. A similar trial called PONDER-ICU () will enrol 4750 patients in the ICU with at least 24 h of mechanical ventilation across ten

hospitals, and test two behavioural economic interventions.⁹⁹ Under the first intervention, physicians working in the ICU will be asked in the patient's electronic medical record if they have offered the option of care focused on comfort and be required to provide justification if they answer no. An important strength of this approach is that it does not require adding personnel to the clinical team, or require existing clinical staff to spontaneously recognise which of their patients might benefit from a palliative approach to care.

The second intervention requires physicians to estimate patients' mortal and functional outcomes before signing future orders, thus concentrating their attention on long-term outcomes. The second intervention leverages the focusing effect, which describes the human tendency to give more weight to elements of choices that are being prompted to be considered,^{101,102} and was shown in a randomised trial⁸¹ of US intensivists reviewing clinical vignettes online. Previous studies by Mosenthal and colleagues,¹⁵ Curtis and colleagues,¹⁹ and White and colleagues²¹ all involved study personnel asking attendings about prognosis, thereby incorporating prompting into their interventions without explicitly identifying it as such. However, one study calls into question whether a prompt is sufficient to change the options ICU proxies are offered. In a double-blind, randomised controlled trial¹⁰³ done in a high-fidelity simulation centre, intensivists prompted to document prognosis were significantly more likely to disclose that the patient was sick enough to die during a simulated family meeting than those who were not prompted to document prognosis, but no more likely to tell the patient's daughter that care focused on comfort was an option.¹⁰⁴

Change might also come from unexpected directions. For example how new ICU follow-up clinics might affect clinical decision-making is unclear.^{105,106} If intensivists staff these clinics, they will have more direct contact with patients surviving an ICU stay. On one hand, seeing the prevalence of cognitive impairment, physical disability, anxiety, and depression experienced by patients surviving an ICU stay might give intensivists pause. On the other hand, seeing only those patients who are healthy enough to travel to outpatient appointments might show a deceptively positive picture of ICU survivorship overall. Other potential sources of new information are the increasingly large and publicly available administrative databases. Intensivists and families sometimes agree to time-limited trials^{106–109} of ICU care or a specific medical therapy to see if a patient will improve. Administrative data might inform these negotiations and complement existing empiric evidence on the long-term outcomes of ICU care.^{110,111}

Finally, patients and family members might demand changes that the medical community has not anticipated yet. In 2011, more than 16 million US citizens, most of whom were middle-aged women, did unpaid caregiving work for elderly relatives.¹¹² These caregivers are increasingly dissatisfied with their loved one's end-of-life care. The proportion of bereaved families in the National Health and Aging Trends Study¹¹³ who reported their loved one received excellent end-of-life care dropped from 353 (57%) of 622 in 2000 to 275 (47%) of 586 in 2013. Family caregivers are also financially pressured. The cost to a daughter's wellbeing of caregiving for an older parent is estimated to range from US\$72 000 to \$100 000 per year.¹¹⁴ As the US population ages, both the number of unpaid family

caregivers and the number of people requiring end-of-life care are projected to rise. Whether ICUs will change how they treat these patients and families, or whether these patients and families will change ICUs, is yet to be seen.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Key messages

- Recognising when intensive care unit (ICU) care is not helping a patient achieve valued goals, and helping that patient and their family embrace achievable goals, related to symptom relief or spiritual fulfilment, are central challenges of critical care in the USA
- Randomised trials of complex communication-focused interventions in the ICU have not shown substantial effects on the long-term mental health symptoms in family members of patients in the ICU, but many of these interventions have resulted in a decreased length of stay, particularly among study participants who die in hospital
- Numerous design and analysis challenges make interpreting trials of interventions that are designed to improve communication between ICU providers, patients, and families difficult
- Clinicians and researchers designing and interpreting studies of communication interventions should be aware of the deep-seated cultural norms and structural aspects of US medical institutions that together contribute to Americans receiving substantially more ICU care during their final month of life than residents of similarly wealthy nations

Panel: Challenges in the design and interpretation of intensive care unit (ICU) communication studies

(1) Limited ability to collect patient-reported outcomes for investigators

- Some patients are too ill to complete surveys at discharge or follow-up, and a substantial proportion of patients die before hospital discharge

(2) No consensus in the field on a target population

- Only enrolling families of patients perceived to be at high risk of death or chronic critical illness potentially re-enforces the idea that structured communication with families of patients in the ICU is only necessary when patients are dying
- Prediction of in-hospital mortality is also imperfect

(3) Enrolling a representative sample of family members is challenging

- Families of patients at highest risk for goal-discordant care are often difficult to enrol in research studies
- Families of patients who receive palliative care participate in research at higher rates, creating potential response bias

(4) Trade-offs to randomising individuals and clusters of patients

- New behaviours are often adopted by an entire ICU team, making them difficult to isolate when individual patients are randomised to treatment
- Cluster randomised trials are appropriate in this context, but decrease a trial's effective sample size and power to detect intervention effects

(5) Steep barriers to process evaluation

- Conversations are the crux of interventions, but data on the content of family meetings is difficult to collect
- Obtaining permission to record family meetings can be challenging

(6) No consensus on a primary outcome

- The field does not have a validated method for assessing whether patients are receiving goal-concordant care
- In its absence, investigators have focused on multiple surrogate outcomes

Search strategy and selection criteria

References for this Series paper were identified through searches of PubMed, Embase, Cochrane Library, and [ClinicalTrials.gov](https://www.clinicaltrials.gov) for original articles about interventions designed to facilitate communication and decision-making in adult ICU patients and their families published from Jan 1, 2008, to August 1, 2018. We used the terms “critical illness” and closely related terms in combination with “patient preference”, “family”, “communication”, and “randomized controlled trial” and their closely related terms. Articles in English identified by these searches and relevant references cited in these articles were reviewed. We also included publications accumulated because of our participation in this field of research.

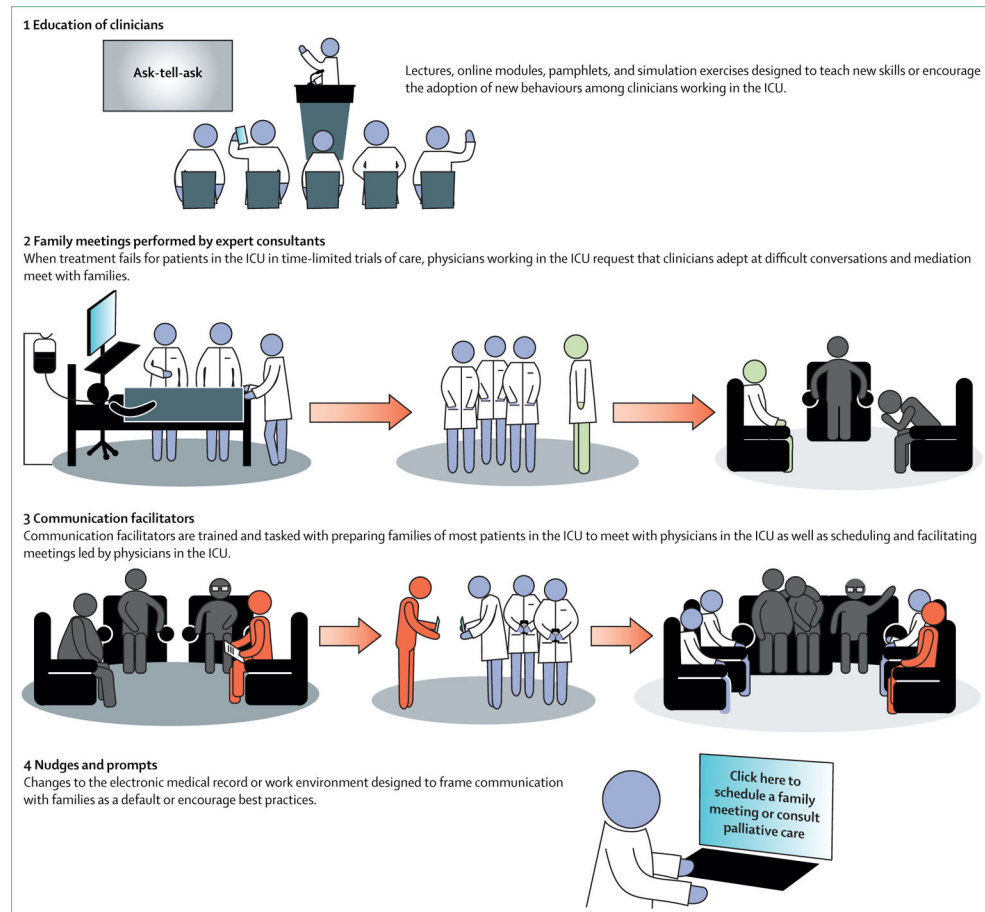


Figure 1: Common elements of interventions designed to improve communication with surrogate decision-makers of patients in the ICU
 ICU=intensive care unit.

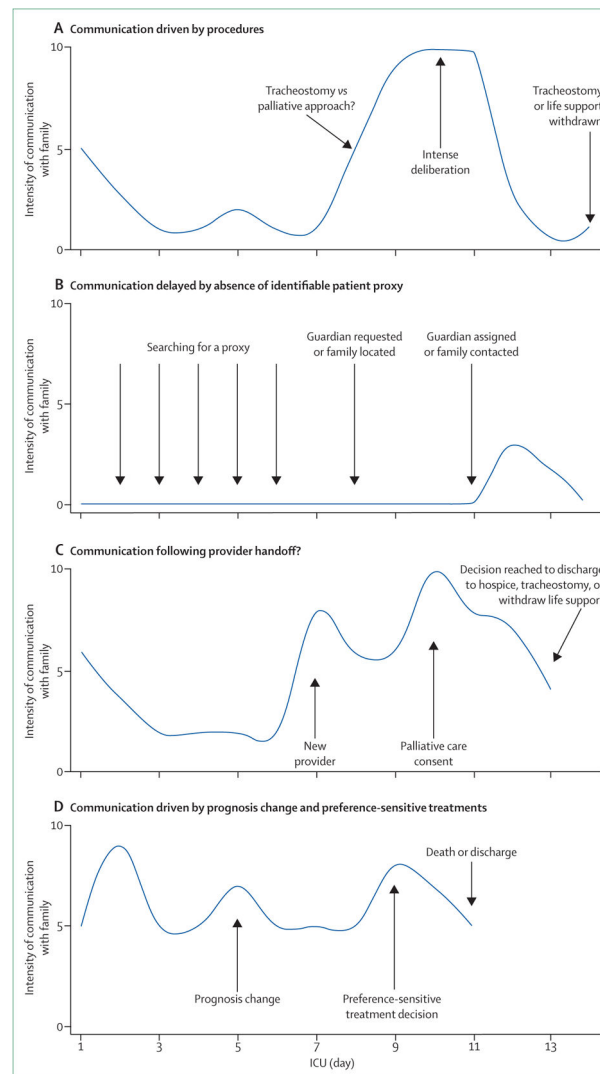


Figure 2: Communication patterns with ICU proxies about patients with prolonged ICU stays
 Panels depict the hypothetical timing and intensity of communication with patient proxies (ie, health-care surrogates, health-care agents, or legal guardians, all of which may or may not be family members) for a patient without decision-making capacity. 1 denotes perfunctory communication (eg, voicemail left) and 10 denotes comprehensive communication (eg, multidisciplinary family meeting).

Table 1:

Study design and results for randomised clinical trials of communication interventions in US adult ICUs (2008–2018)

	Curtis and colleagues, ¹⁸ 2011	Curtis and colleagues, ¹⁹ 2016	Carson and colleagues, ²⁰ 2016	White and colleagues, ²¹ 2018
Patient inclusion criteria	Died in the ICU or within 30 h of transfer to another hospital location	24 h ICU stay, mechanically ventilated; and SOFA 6 or 30% chance of hospital mortality *	7 days of mechanical ventilation uninterrupted for 96 h and not expected to wean from mechanical ventilation or die in <72 h	No capacity, and 4 days mechanical ventilation, or 40% chance of hospital death or long-term impairment *
Families enrolled	822	268	365	1106 [‡]
Brief intervention description	The intervention addressed ICU-specific barriers, clinicians' education, feedback on family satisfaction, and introducing palliative care order forms	The interventionists interviewed families, provided support adapted to the family's attachment style, and participated in family meetings	The interventionists held a premeeting with the ICU team, then met with the family and provided a brochure on chronic critical illness; optional for ICU attending to participate in family meetings	The interventionists arranged and participated in family meetings with ICU attendings; families completed a question prompt list before each meeting
Timing, frequency, or dose of intervention	..	Mean of 9.4 facilitator contacts and 267 min per family	Interventionist-led family meeting after 7 days of mechanical ventilation, then about every 10 days	Interventionists met with families daily, arranged a family meeting in 48 h, then every 5–7 days
Primary outcome	QODD questionnaire: family assessed 4–6 weeks after patient death	PHQ-9; family assessed 3 and 6 months after ICU discharge	HADS; family assessed 3 months after ICU discharge	HADS; family assessed 6 months after ICU discharge
Primary outcome score				
Control vs intervention	QODD: 64 vs 61, p=0.33	3 months: 5 vs 3; p=0.10 6 months: 5 vs 3; p=0.02	11 vs 12, p=0.45; (adjusted)	12 vs 12, p=0.61 (adjusted)
Died during this hospitalisation				
Control vs intervention	..	37% vs 27%, p=0.20	40% vs 38%, P=0.65	30% vs 38%, p=0.008 (adjusted)
Mean length of stay in days				
Control vs intervention	..	33 vs 24, p=0.001	23 vs 19, p=0.51	16 vs 12, p<0.001 (adjusted)

IRB decided all baseline activities counted as Quality Improvement. HADS=hospital anxiety and depression score. ICU=intensive care unit. PHQ-9=patient health questionnaire. SOFA=Sequential Organ Failure Assessment. QODD= quality of death and dying.

* Probability of in-hospital death or long-term impairment on the basis of attending MD's assessment.

[‡] Family members were not enrolled until follow-up.

Table 2:

Ongoing and planned clinical trials of communication interventions in US adult ICUs

	Description	Primary Outcome
Facilitating communication study ()	Follow-up to the 2016 trial by Curtis and colleagues ²⁰ of an intervention using nurses working in the ICU as facilitators to support, model, and teach communication strategies over an illness trajectory, beginning in the ICU and continuing to care in the community	Family symptoms of anxiety and depression (HADS)
The four supports study ()	Follow-up to the 2018 trial by White and colleagues ²¹ designed to evaluate the effectiveness of a multifaceted communication intervention as compared with an educational control among family members of critically ill patients; now with audio recording of intervention encounters to assess fidelity	Family symptoms of anxiety and depression (HADS)
Randomised evaluation of default access to palliative services ()	Large pragmatic trial testing a default order for a palliative care consult for older patients (>65 years) with a diagnosis of chronic obstructive pulmonary disease, end-stage renal disease, or dementia and a hospital stay of at least 72 h	Composite measure of length of stay and in-hospital mortality
Prognosticating outcomes and nudging decisions with electronic records in the ICU ()	Pragmatic, stepped-wedge, cluster randomised trial testing two different electronic health record behavioural interventions among seriously ill hospitalised patients	Composite measure of length of stay and in-hospital mortality

HADS=hospital anxiety and depression score. ICU=intensive care unit.