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ORIGINAL

# Modifiable elements of ICU supportive care and communication are associated with surrogates' PTSD symptoms

Blair Wendlandt[1*], Agathe Ceppe[1], Summer Choudhury[1], Christopher E. Cox[2], Laura C. Hanson[1], Marion Danis[3], James A. Tulsky[4], Judith E. Nelson[5] and Shannon S. Carson[1]



## Abstract

**Purpose:** To identify specific components of ICU clinician supportive care and communication that are associated with increased post-traumatic stress disorder (PTSD) symptoms for surrogate decision makers of patients with chronic critical illness (CCI).

**Methods:** We conducted a secondary analysis of data from a randomized controlled trial of palliative care-led meetings to provide information and support for CCI surrogates. The primary outcome for this secondary analysis was PTSD symptoms at 90 days, measured by the Impact of Event Scale-Revised (IES-R). Caregiver perceptions of clinician support and communication were assessed using a version of the After-Death Bereaved Family Member Interview (ADBFMI) instrument modified for use in non-bereaved in addition to bereaved caregivers. The association between ADBFMI items and IES-R score was analyzed using multiple linear regression.

**Results:** Ninety-day follow up was complete for 306 surrogates corresponding to 224 patients. Seventy-one percent of surrogates were female, and the mean age was 51 years. Of the domains, negative perception of the patient's physical comfort and emotional support was associated with the greatest increase in surrogate PTSD symptoms (beta coefficient 1.74, 95% CI 0.82–2.65). The three specific preselected items associated with increased surrogate PTSD symptoms were surrogate perception that clinicians did not listen to concerns (beta coefficient 10.7, 95% CI 3.6–17.9), failure of the physician to explain how the patient's pain would be treated (beta coefficient 12.1, 95% CI 4.9–19.3), and lack of sufficient religious contact (beta coefficient 11.7, 95% CI 2–21.3).

**Conclusion:** Modifiable deficits in ICU clinician support and communication were associated with increased PTSD symptoms among CCI surrogates.

**Keywords:** Surrogate decision maker, Chronic critical illness, Post-traumatic stress disorder, Supportive care, Clinician communication

*Correspondence: blair.wendlandt@unchealth.unc.edu
[1] University of North Carolina School of Medicine, 130 Mason Farm Road CB#7020, Chapel Hill, NC 27599, USA
Full author information is available at the end of the article

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## Introduction

Chronic critical illness (CCI) is a syndrome characterized by prolonged multi-system organ failure resulting in dependence on supportive therapies such as mechanical ventilation for more than 7 days. The incidence of CCI in the US is approximately 100,000 patients per year, and 1-year mortality ranges from 48 to 68% [1]. For those who do survive, prior outcome studies have shown significant long-term cognitive and physical disability, with two thirds of patients displaying persistent cognitive impairment at 6 months and 75% of patients requiring assistance with one or more activities of daily living (ADLs) 1 year after CCI onset [2, 3]. As a result, these patients are often dependent on family members for surrogate decision-making in the ICU and for assistance with daily functioning after hospital discharge [4].

Poor health-related quality of life [5], as well as anxiety, depression, and post-traumatic stress disorder (PTSD) have been described in family caregivers of patients with critical illness [6, 7], with one study finding that approximately one third of caregivers had post-traumatic stress symptoms consistent with a moderate to major risk of PTSD. This cluster of adverse symptoms and emotional distress is referred to as the post-intensive care syndrome-family (PICS-F) [8]. With prolonged hospitalization, multiple acute complications, and poor outcomes associated with chronic critical illness [1], this syndrome may be especially severe for caregivers of the chronically critically ill. Caregiver distress can impair attention, memory [9], and medical decision making [10], thus carrying the potential to negatively impact long-term outcomes for CCI patients. Some randomized trials show that enhanced clinician communication might help mitigate surrogate decision-maker distress in the ICU [11, 12], yet many carefully designed communication interventions have failed to show a significant positive impact [13–15]. Although one study assessed elements of communication and support as risk factors for PTSD in bereaved surrogates of patients who died [16], no prior study has specifically examined which elements of support and communication are most strongly associated with PTSD in surrogates of patients with CCI [7, 17, 18].

Our objective was to identify potential intervention targets for improving long-term psychological distress among surrogates of the chronically critically ill by determining if modifiable elements of ICU clinician supportive care and communication were associated with increased PTSD symptoms.

**Take-home message**

Increased surrogate PTSD symptoms were associated with modifiable deficits in ICU clinician supportive care and communication, including clinicians' failure to listen to concerns and explain how the patient's pain would be treated, and lack of sufficient religious contact.

## Methods

### Data source

We performed a secondary analysis of data from a multicenter, randomized controlled trial designed to determine whether structured family informational and emotional support meetings led by palliative care specialists improved emotional outcomes for surrogate decision-makers of CCI patients when compared with routine care provided by the primary ICU team [13]. Trial participation was offered to adult patients in four medical ICUs with at least 7 days of mechanical ventilation and determination by the ICU physician that the patient was not expected to be liberated from the ventilator nor die in the next 72 h. These criteria, which typically are considered in decision-making about tracheotomy and other options, represent a practical and accepted point of demarcation between acute and chronic critical illness. Study participation was offered to two categories of surrogate decision-makers: the primary surrogate designated as having responsibility for health care decision-making if the patient lacked capacity, and additional surrogate decision-makers who participated in health-care decision-making for the patient. Patients who had chronic neuromuscular disease, trauma, or burns were excluded because they have a different clinical course and prognosis [1]. The intervention did not reduce surrogate depression or anxiety symptoms compared to usual care, and may have increased symptoms of post-traumatic stress disorder. The trial database contains demographic and medical information for 256 CCI patients, as well as demographic information, 90 day outcomes for psychological distress, and reports on perceived quality of support and communication from 365 associated surrogates. Three-month follow-up was complete for 306 (84%) of enrolled surrogates, corresponding to 224 patients. All patients and surrogates from both intervention and control groups in the trial with complete 3-month follow-up data were pooled for this secondary analysis.

#### *Primary outcome measure*

The presence and severity of surrogate PTSD symptoms were assessed through telephone interviews at 90 days post-randomization using the Impact of Events

Scale-Revised (IES-R), an instrument validated among families of ICU survivors and non-survivors [19]. The 22-item IES-R includes three subscales, thought intrusion, avoidance, and hyperarousal, asking respondents to rate "how distressing each difficulty has been." Summed subscale scores for IES-R range from 0 to 88 with higher scores indicating worse symptoms, and a minimal clinically important difference (MCID) of approximately 4.0 [20]. A score $\geq 33$ is a cut-off used to identify a level of PTSD-related symptoms that is consistent with a probable diagnosis of PTSD [19].

#### *Predictor variables*

Surrogates also completed the After-Death Bereaved Family Member Interview (ADBFMI) [21] at 90 days. The ADBFMI was one of three validated instruments used in the original clinical trial to elicit family perceptions of ICU care for comparison between the intervention and control groups (the other measures were the FS-ICU [22] and Quality of Communication [23] scales). The ADBFMI data were used for this secondary analysis based on the investigators' a priori judgment that this instrument's rich and comprehensive measures of perceptions of patient care, clinician-family support, and communication would be best suited to the research question. The ADBFMI was minimally modified for the clinical trial in two ways: (1) questions specific to the dying process were omitted if not applicable so that the instrument could be administered to surrogates of patients who survived to 90 days in addition to surrogates of patients who died, and (2) question wording was changed slightly to specifically focus on the time that the patient was under the care of the ICU since that was the period relevant to the clinical trial intervention and future interventions involving critical care providers. In the original trial, no differences were found on this instrument between intervention and control groups.

The ADBFMI elicits surrogate ratings of care across the following five domains: physical comfort and emotional support, provision of information and promotion of shared decision-making, encouragement of advance care planning, focus on the individual patient, and attention on the spiritual and emotional needs of surrogates. Each domain contains three to eight categorical response questions addressing patient-focused care or family-centered care, including aspects of clinician communication. The "problem score" for each domain is calculated using the sum of negative responses to individual questions within the domain divided by the number of questions within the domain; problem scores range from 0 to 1, and a higher score represents more concerns with the quality of care and communication. During development and validation of the ADBFMI instrument, questions within each domain were designed to assess either unmet respondent needs or patient-centered items. For these 13 patient-centered questions, dichotomous response options were utilized to obtain results that could be acted upon if deficits were identified [21]. Additionally, there is an overall summary scale comprised of five questions asking surrogates to rate the degree to which patient focused, family-centered care was provided by the clinical team on a scale from 0 (worst) to 10 (best).

#### *Analyses*

To identify elements of clinician supportive care and communication associated with the primary outcome of surrogate PTSD symptoms, we examined potential associations between the five problem scores of the modified ADBFMI and the continuous IES-R score using a mixed model, adjusting for multiple respondents and considering the patients as a random factor. As a pre-planned exploratory analysis, we also used this approach to evaluate associations between surrogate PTSD symptoms and the 13 individual patient-centered (yes/no) items in the ADBFMI. These items were targeted because they represent patient-centered items that are considered by the instrument developers as "actionable" components of clinician communication, or practices that could be improved if deficits are identified [21]. The individual patient-centered items are shown in Table 3 under their relevant domains.

Based on prior work showing that surrogate anxiety and depression (measured by the Hospital Anxiety and Depression Scale [HADS], score range 0 [best] to 42 [worst] [24]) and patient unresponsiveness (measured by the Richmond Agitation and Sedation Scale [RASS], score range $-5$ [unarousable] to $+4$ [combative]; 0 represents normal arousal [25]) on or near day 10 of mechanical ventilation are risk factors for surrogate PTSD symptoms [26], we also adjusted our analyses for these factors. Additional covariates in the analyses in the present study included site and intervention group from the original clinical trial (clinicaltrials.gov identifier NCT01230099) [13], duration of patient mechanical ventilation, and patient mortality at 90 days. Patient and surrogate demographics, patient co-morbidities and severity of illness were not associated with surrogate PTSD symptoms in previous analyses [26], and thus were not included in modeling.

Descriptive statistics were performed using mean and 95% confidence interval for continuous variables and frequency and percentage for categorical variables. Analysis was performed using SAS 9.4 (SAS Institute Inc).

**Table 1 Baseline characteristics of surrogate decision-makers**

| Characteristic | Surrogates ($n=306$) |
|---|---|
| Age, mean (95% CI), years | 51 (49.3–52.4) |
| Female sex, no. (%) | 218 (71) |
| Ethnicity, no. (%) | |
| Hispanic or Latino | 38 (12) |
| Not Hispanic or Latino | 267 (88) |
| Race, no. (%) | |
| Black | 72 (24) |
| Caucasian | 193 (63) |
| Other | 41 (13) |
| Employment, no. (%) | |
| Unemployed | 27 (9) |
| Disabled from employment | 30 (10) |
| Employed/student | 168 (55) |
| Homemaker | 22 (7) |
| Retired | 58 (19) |
| Religion, no. (%) | |
| Catholic | 56 (18) |
| Jewish | 17 (6) |
| Protestant | 200 (66) |
| Other | 16 (5) |
| None | 16 (5) |
| Relationship, no. (%) | |
| Child | 109 (36) |
| Parent | 41 (13) |
| Sibling | 37 (12) |
| Spouse/partner | 100 (33) |
| Other | 19 (6) |
| Number of decision makers per patient, no. (%) | |
| 1 | 152 (50) |
| 2 or more | 154 (50) |
| Hospital Anxiety and Depression Scale score at baseline, mean (95% CI) | |
| Total[a] | 16 (15.1–16.9) |
| Anxiety subscale[b] | 10 (9–10.1) |
| Depression subscale[b] | 7 (6–7) |

[a] The range is 0 (best) to 42 (worst)

[b] The range is 0 (best) to 21 (worst). A score $\geq 11$ on either subscale suggests the presence of anxiety and/or depression disorder(s); scores from 8 to 10 may represent "borderline" symptom levels

## Results

A total of 306 of 365 (84%) randomized surrogate decision makers for 224 associated CCI patients were included (Tables 1, 2). Seventy-one percent of surrogates were female, and their mean age was 51 (95% CI 49.3–52.4) years old. The majority of surrogates were either the spouse/partner or adult–child of the patient. Mean score for the anxiety subscale of the HADS measured at the time of enrollment in the clinical trial was 10.0 (95% CI 9.0–10.1), indicating borderline high symptoms for the average surrogate. Mean score for the depression subscale of the HADS measured at the time of enrollment in the clinical trial was 7.0 (95% CI 6.0–7.0). Mean IES-R score at 90 days was 23.3 (95% CI 21.3–25.4).

Half the patients were female, and patient mean age was 59 years (95% CI 56.4–60.7). Ninety-five patients (44%) had a RASS score of −4 or −5 (i.e., stupor or coma) at day 10 of mechanical ventilation (Table 2). Mean duration of mechanical ventilation was 21 days (95% CI 13.1–28.8). Ninety-four patients (43%) died before the 90-day follow-up interview.

Surrogate concerns about care related to the patient's physical comfort and emotional support (reflected by the problem score for this ADBFMI domain) had the largest association with surrogate PTSD symptoms as measured by the IES-R score, as a 0.1 unit increase (scale 0–1.0) in the corresponding ADBFMI domain problem score was associated with a 1.74-unit increase in IES-R score (95% CI 0.82–2.65; $p=0.0003$) (Table 3). Accordingly, a 0.3 increase in this problem score would be associated with a clinically significant increase in surrogate PTSD symptoms. For the ADBFMI domain of facilitating advance care planning, a 0.1 unit increase in the level of surrogate concern was associated with a 0.75-unit increase in IES-R score (95% CI 0.12–1.39; $p=0.02$). A 0.1 unit increase in the ADBFMI problem score for providing information and promoting shared decision-making was associated with a 0.8-unit increase in IES-R score at 90 days (95% CI 0–1.59; $p=0.05$), but did not reach statistical significance. Other ADBFMI domains had no statistically significant associations with IES-R scores.

Analysis of the five item summary scale (range 0–10) showed that surrogates were generally highly satisfied with patient-focused, family centered care. However, lower ratings on this scale indicating lower satisfaction were associated with higher PTSD risk. A one unit decrease in the overall rating scale for patient focused, family centered care was associated with a 2.2 unit increase in the IES-R score (95% CI 0.9–3.5; $p=0.001$).

In the exploratory analysis of 13 pre-selected individual patient-focused ADBFMI items, we found that the greatest increases in PTSD symptoms at 90 days were associated with three items (Table 3) that describe clinician behaviors: failure to listen to surrogates' concerns, failure of the doctor or medical staff to explain how the patient's pain would be treated, and failure to provide surrogates with sufficient religious support personnel contact while the patient was in the ICU. Compared to surrogates who received explanations of pain treatment or sufficient religious contact, surrogates who reported not receiving such supports had mean IES-R scores that were 12.1 units higher (95% CI 4.9–19.3; $p=0.001$) and 11.7 units

**Table 2 Baseline characteristics of patients**

| Characteristic | Patients ($n=224$) |
|---|---|
| Age, mean (95% CI), years | 59 (56.4–60.7) |
| Female sex, no. (%) | 109 (49) |
| Race, no. (%) | |
| Black | 53 (24) |
| Caucasian | 138 (63) |
| Unavailable | 17 (8) |
| Other | 10 (5) |
| Activities of daily living score, mean (95% CI)[a] | 5 (4.6–5.2) |
| Instrumental activities of daily living score, mean (95% CI)[b] | 16 (14.8–16.9) |
| 1-year mortality as predicted by ProVent score, mean % (95% CI) | 62 (58.6–64.8) |
| Richmond Agitation Sedation Scale at enrollment, no. (%) | |
| −5 or −4 (unresponsive) | 95 (44) |
| −3 to −1 (arousable) | 81 (38) |
| 0 and above (awake) | 38 (18) |
| Hospital length of stay prior to trial enrollment, mean (95% CI), d | 13 (11.8–13.5) |
| Death by 90 days, no. (%) | 94 (43%) |

[a] The range is 0 (dependent) to 6 (independent) in six activities

[b] The range is 8 (dependent) to 31 (independent) in eight activities

higher (95% CI 2.0–21.3; $p=0.02$), respectively. The mean IES-R score among surrogates who reported physicians did not listen to their concerns was 10.7 units higher (95% CI 3.6–17.9; $p=0.009$) than surrogates who felt that their concerns were heard.

Surrogates who felt that medical procedures and treatments were not consistent with patient wishes or that physicians did not discuss patient wishes for medical treatment with them had higher IES-R scores, [6.5 (0–12.9), $p=6.5$; and 5.1 (0–10.1), $p=0.05$ units, respectively] but associations did not reach statistical significance.

## Discussion

This is the first study to our knowledge that details specific modifiable elements of ICU communication and support that are associated with PTSD in surrogate decision makers of patients with chronic critical illness. Of the overall domains of supportive care and communication, we found that a high level of surrogate concern with the patient's physical comfort and emotional support during hospitalization was associated with the largest increase in surrogate PTSD symptoms at 90 days. The modifiable patient-centered items that were associated with the greatest increase in PTSD symptoms were surrogate perception that the patient's physicians did not listen to concerns, medical treatments were not consistent with patient wishes, surrogate perception that doctors or medical staff did not explain how the patient's pain would be treated, and not having the desired amount of religious contact while the patient was in the ICU.

Interventions to reduce long-term emotional distress in surrogate decision-makers have met with limited success in rigorous clinical trials to date [11, 13, 14, 27, 28], and our findings provide actionable data that can inform targeted strategies to improve outcomes for surrogate decision-makers of critically ill patients. In addition to the obvious importance to patient well-being, patient and family satisfaction with the clinician listening to their concerns and with explanation of pain management strategy are now key measures of performance quality in the US healthcare system [29, 30].

Several recent studies highlight the need for data to inform clinicians on how to enhance communication and supportive care for surrogate decision makers in the ICU. A 2017 study by Swinton and colleagues demonstrated that, regardless of baseline religiosity, a patient's end-of-life experience in the ICU is widely viewed by family decision makers as a spiritual experience and that families expressed a variety of spiritual and religious needs while in the ICU [31]. A multicenter study of key stakeholders found that a majority of family surrogates, clinicians, and non-clinician experts identified increased attention to family emotional support as an important concept when caring for the critically ill [32]. Torke and colleagues found that higher satisfaction with communication was associated with lower symptoms of PTSD in surrogate decision makers of elderly patients admitted to the hospital, but this cohort included patients both on the wards

**Table 3 Results of after death bereaved family member interview domains and patient-centered questions**

| Domain name and associated patient-centered questions | Problem score (95% CI) | Respondents answering "No", no. (%) | Change in IES-R score associated with a "No" response (95% CI) | *p* value |
|---|---|---|---|---|
| Patient physical comfort and emotional support[a] | 0.13 (0.11 to 0.15) | | 1.74 (0.82 to 2.65) | 0.0003 |
| Did the doctor or the medial staff explain how patient's pain would be treated? | | 20 (7%) | 12.1 (4.9 to 19.3) | 0.001 |
| Was there ever a time when different clinicians said different things about treatment of pain? | | 223 (82%) | −7 (−11.3 to −2.7) | 0.002 |
| Inform and promote shared decision-making[a] | 0.17 (0.14 to 0.2) | | 0.8 (0 to 1.59) | 0.05 |
| Did you ever have trouble understanding what any doctor said about what to expect from treatment? | | 224 (77%) | 1 (−3.7 to 5.6) | 0.67 |
| Did you feel that doctors listened to your concerns about medical treatment?[b] | | 23 (8%) | 10.7 (3.6 to 17.9) | 0.009 |
| Was there ever a decision made about patient without input from family? | | 257 (85%) | 2 (−7.3 to 3.3) | 0.46 |
| Focus on individual[a] | 0.2 (0.17 to 0.23) | | 0.71 (−0.11 to 1.53) | 0.09 |
| Was there enough help available to meet the patient's care needs? (bathing, dressing, bed change) | | 19 (6%) | −0.5 (−9 to 7.9) | 0.91 |
| Was there enough help with medications and getting dressings changed? | | 15 (5%) | 1.1 (−8.5 to 10.8) | 0.82 |
| Family emotional and spiritual support[a] | 0.21 (0.19 to 0.23) | | 0.68 (−0.26 to 1.62) | 0.16 |
| Did you have enough religious contact as you might have wanted while in the hospital? | | 10 (5%) | 11.7 (2 to 21.3) | 0.02 |
| Did a doctor, nurse or staff suggest someone you could turn to for help if you were stressed? | | 122 (41%) | 2.2 (−1.7 to 6.1) | 0.26 |
| Did someone talk to you about your religious beliefs? | | 112 (37%) | 2.2 (−1.8 to 6.3) | 0.27 |
| Encourage advance care planning[a] | 0.15 (0.12 to 0.19) | | 0.75 (0.12 to 1.39) | 0.02 |
| Were medical procedures and treatments consistent with patient wishes? | | 28 (10%) | 6.5 (0 to 12.9) | 0.05 |
| Did the patient's doctor speak to you about wishes for patient's medical treatment? | | 53 (18%) | 5.1 (0 to 10.1) | 0.05 |
| Did the patient's doctor speak to you about making sure care was consistent with patient wishes? | | 47 (16%) | 4.8 (0.4 to 10) | 0.07 |
| Overall rating scale for patient focused, family centered care[c] | 8.82 (8.65 to 9.0) | | 2.2 (0.9 to 3.5) | 0.001 |

Associations for problem scores and individual questions were adjusted for baseline family member Hospital Anxiety and Depression Score ($p = < 0.0001$), patient level of responsiveness at enrollment ($p = 0.0066$), study site ($p = 0.217$) and clinical trial intervention ($p = 0.0495$), duration of mechanical ventilation ($p = 0.115$), and patient death by the time of 90 day follow up ($p = 0.0002$)

[a] Each domain contains three to eight questions, with a problem score for each calculated using the sum of negative responses to individual questions within the domain divided by the number of items within the domain. The problem score ranges from 0 to 1.0, with a higher score representing more concerns with the quality of care. For example, in the domain "Patient physical comfort and emotional support", each 0.1 in the level of surrogate concern was associated with an increase of 1.74 (95% CI 0.82–2.65) in IES-R score. The IES-R score is on a 0–88 scale with higher scores representing more PTSD symptoms

[b] Question also contained a "no concerns" option, coefficient 20.7 (95% CI 1.4–39.9)

[c] The overall rating scale contains five individual questions rating overall patient-focused and family centered care on a scale from 0 (worst) to 10 (best). The overall scale score is calculated as an average of the responses to the individual questions. A higher score represents fewer concerns with the quality of care. For example, a decrease of 1 unit on the overall scale score is associated with a 2.2 (95% CI 0.9–3.5) increase in the IES-R score

and in the ICU, severity of illness was generally low, and specific elements of communication were not assessed [33]. Azoulay and colleagues found that family perception that information in the ICU was incomplete was associated with increased PTSD symptoms at 90 days, but further data were not provided regarding which elements of communication were perceived as being incomplete by the surrogate decision makers [7]. A randomized clinical trial by Lautrette and colleagues [12] found that a brochure on bereavement and a proactive end-of-life conference reduced symptoms of anxiety and depression and PTSD at 90 day follow-up among relatives of patients approaching death in ICUs in France. Our findings suggest that a few specific modifications to ICU clinician practice—eliciting surrogate concerns, specifically explaining the pain management plan, making timely referral to chaplaincy or encouraging involvement of the patient's or surrogates' own spiritual supports—could

potentially reduce PTSD symptoms for surrogate decision makers. Education resources are available to assist clinicians in enhancing their communications skills [34].

Our study has several limitations. The ADBFMI has been validated in bereaved surrogates only and was modified here to allow for use in non-bereaved family surrogates as well. However, most of the elements of support and communication measured by this instrument were associated with a significant change in PTSD symptoms even after adjusting for patient death in a multivariable model, suggesting that this content is applicable to both bereaved and non-bereaved surrogates. Additionally, the results of the ADBFMI are generally interpreted using composite problem scores rather than responses to each individual question, and our utilization of both represents a different approach that has recent precedent in the medical literature [35]. As such, results for analyses of specific items should be considered exploratory in nature. Third, both surrogate perceptions of support and communication and symptoms of PTSD were measured together at 90 days and did not take into account pre-existing psychological issues, which could have been significant since anxiety and depression scores were in the borderline high range for surrogates at study enrollment. Therefore a causal relationship between support and communication and symptoms of PTSD cannot be determined with certainty. Additionally, this is a secondary analysis of data from a randomized clinical trial. Finally, because we included only medical ICU patients with chronic critical illness from four hospitals in the US, generalizability to surrogates of surgical patients or critically ill patients in other countries or cultures may be limited.

In conclusion, perceptions by family surrogate decision makers of patients with chronic critical illness that ICU clinicians did not listen to concerns, did not explain how patients' pain would be treated, and did not provide the desired amount of religious support were identified as potential modifiable deficits in clinician support and communication that could form the basis of future interventions to reduce surrogate decision-maker distress.

**Author details**
[1] University of North Carolina School of Medicine, 130 Mason Farm Road CB#7020, Chapel Hill, NC 27599, USA. [2] Duke University Medical Center, Durham, NC, USA. [3] National Institutes of Health, Bethesda, MD, USA. [4] Dana Farber Cancer Institute, Brigham and Women's Hospital, Harvard Medical School, Boston, MA, USA. [5] Memorial Sloan Kettering Cancer Center and Weill-Cornell Medical College, New York, NY, USA.

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**Compliance with ethical standards**

**Conflicts of interest**
The authors declare that they have no conflicts of interest.

**Ethical approval**
An approval by an ethics committee was not applicable.

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