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Failures in the Respectful Care of Critically Ill Patients

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Abstract

Background: The emotional toll of critical illness on patients and their families can be profound and is emerging as an important target for value improvement. One source of emotional harm to patients and families may be care perceived as inadequately respectful. The prevalence and risk factors for types of emotional harms is under-studied.

Methods: This prospective cohort study was conducted in nine ICUs at a tertiary care academic medical center in the United States. Prevalence of inadequate respect for (a) the patient and (b) the family, as well as prevalence of perceived lack of control over the care of their loved ones, was assessed by the Family Satisfaction with Care in the Intensive Care Unit instrument. The relationship between these outcomes with demographic and clinical covariates was assessed. Stratification by patient survivorship was performed in sensitivity analysis.

Results: Of more than 1,500 respondents, 16.9% and 21.8% reported that the patient or the family member, respectively, received inadequate respect. No clinical characteristics of the patients were associated with inadequate respect for either the patient or the family member. By comparison, more than half of respondents reported a lack of control over their loved one's care; this finding was associated with multiple clinical factors. Prevalence and associated factors differed by patient survivorship status.

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Conclusion: Care that is inadequately respectful to patients and families in the setting of critical illness is prevalent but does not appear to be associated with clinical characteristics. The incidence of such emotional harms is nuanced, difficult to predict, and deserves further investigation.

Care of the critically ill patient has improved for both patient outcomes and patient safety.¹⁻³ However, clinicians and researchers have increasingly recognized the emotional toll of critical illness on patients and their families. Recent studies estimate that around one quarter of patients,^{4,5} and between one quarter and one half of family members,⁶⁻⁸ experience anxiety, depression, or post-traumatic stress following an ICU hospitalization—all potential signs of post-intensive care syndrome.^{9,10}

One source of potential emotional harm for patients and families may be care they perceive as inadequately respectful, thereby violating their dignity.^{11,12} *Respect* has previously been defined as “the sum of the actions we take to protect, preserve and enhance the dignity of our patients.”^{11(p. 551)} In the ICU, where disease severity and care coordination are at their most complex, patients and families are at particularly high risk of receiving care that fails to protect their intrinsic value as human beings.^{11,13,14} Care that is inadequately respectful includes privacy breaches (for example, failure to cover the patient’s body during examinations), communication breakdowns (for example, delivery of insufficient, confusing, and/or conflicting information about the patient’s prognosis), and failures to understand what matters to patients and families (for example, ignorance of a patient’s preference for palliative care over life-sustaining medical treatment at end of life). Care that is inadequately respectful can be dehumanizing, can permanently damage patient-provider relationships, and can lead to long-lasting adverse effects on both psychological and physical health.¹⁵ Moreover, some argue that disrespectful care, even when it does not lead to measurable psychologic distress, is intrinsically both a harm and a wrong.¹² As such, inadequately respectful care should be examined as rigorously as other avoidable physical harms already targeted by patient safety movements. However, the prevalence of failures of respect for patients and families in the ICU is unknown.

We (1) quantified the prevalence of inadequate respect, courtesy, and compassion for (a) the patient and (b) the family; (2) quantified the prevalence of perceived lack of control over the care of their loved ones; and (3) assessed whether emotional harm or lack of control over care was related to patient, family, and provider characteristics. Although inadequately respectful care is universally undesirable, a lack of control—while an emotional experience—is not necessarily undesirable and therefore served as a useful point of comparison. We hypothesized that perceptions of inadequate respect and lack of control would be common and that there would be potentially modifiable risk factors associated with both.

MATERIALS AND METHODS

Design, Setting, and Patients

This was a prospective observational cohort study conducted between April 2008 and February 2015 in a tertiary care teaching hospital in Boston. This institution has nine adult, closed ICUs with 77 beds. The nine ICUs provide different types of care, including medical ($n = 3$), general surgery ($n = 1$), trauma ($n = 1$), coronary ($n = 1$), cardiac surgery ($n = 2$),

and neurology ($n = 1$). Units were open to overflow (patients on a medical service can be boarded in a surgical unit). Subjects were eligible if they (1) were the adult family member of an adult ICU patient with ICU stay >24 hours and (2) could communicate in English. The survey was completed by family members within three days of discharge from the ICU or, in the case of nonsurviving patients, was mailed to the proxy's home seven weeks after death, with a single reminder letter four weeks later to non-responders. All respondents were included in the analysis.

Our study was approved by the Institutional Review Board at the Beth Israel Deaconess Medical Center. The requirement of informed consent and authorization for disclosure of protected health information was waived.

Survey Instrument

The Family Satisfaction with Care in the Intensive Care Unit instrument (FS-ICU) is a 34-item instrument designed to measure family satisfaction with the critical care experience.¹⁶ It has been validated in multicenter,¹⁷ international,¹⁸ and multicultural¹⁹ cohorts. At our institution, the FS-ICU was administered as part of a larger quality improvement effort beginning in 2007. Other findings from this endeavor have been published previously.^{20,21} To ensure minimization of bias, interviewers were formally trained by a PhD methodologist.

Outcomes

Our two primary outcomes of interest were the prevalence of (1) the perception of inadequate respect for the patient and (2) the perception of inadequate respect for the family. Our secondary outcome was family report of lack of control over care. These three outcomes were measured using items of the FS-ICU survey (Questions 1.1, 1.7, and 2.11, respectively) that ask family members to rate (1) "courtesy, respect, and compassion" toward the patient (hereafter abbreviated as "respect for patient"), (2) "courtesy, respect, and compassion" toward the family member (hereafter abbreviated as "respect for family"), and (3) the feeling of "control over the care [of the patient]." All three items are 5-point Likert-type items ranging from "excellent" to "poor" for items 1 and 2, and "really out of control" to "good control" for item 3. Because responses were strongly skewed toward "excellent"/"good control," we dichotomized responses into "optimal" when the "excellent"/"good control" rating was selected and "inadequate"/"lack of control" when any other rating was chosen. Dichotomization of Likert-type items is a valid method of analyzing highly skewed responses.²² Dichotomization also improves interpretability for patients, families, and clinicians. Drawing a distinction between the most positive response and other responses has been used in prior FS-ICU literature^{20,23} and with other forms of public reporting of patient satisfaction.²⁴ The selection of this threshold highlights the difference between an optimal and an imperfect experience.

Covariates Present on Admission

Exposure variables of interest included patient characteristics (age, sex, race, primary diagnosis, type, and number of comorbidities) and family characteristics (age, sex, relationship to the patient, involvement in the patient's care prior to admission, and living arrangement with the patient and hospital prior to admission).

Clinical Covariates

Exposure variables related to the ICU course included primary service (medical vs. surgical service); presence of residents on the primary team; utilization of any form of life-support therapy—defined as mechanical ventilation, vasopressors, or initiation of dialysis; number of central lines, procedures, and radiology studies (identified via CPT® [Current Procedural Terminology] codes); ICU length of stay; and maximum score on the Richmond Agitation-Sedation Scale.²⁵

Statistical Analyses

The unit of analysis was hospital admission. We determined the prevalence of our primary and secondary outcomes, as well as the prevalence of experiencing any one or all three outcomes. We used Fisher's exact tests or *t*-tests for unadjusted tests of difference between those reporting inadequate respect or control and those reporting optimal respect or control. We calculated unadjusted odds ratios (ORs) with 95% confidence intervals (CIs) to determine the strength of association between each clinical or demographic covariate and outcome of interest. Using logistic regression, we created a multivariable model that included variables that were significant ($p < 0.05$) on univariate analysis and potential confounders of those univariate-outcome relationships. All statistical tests were performed using SAS 9.4 (SAS Institute Inc., Cary, North Carolina).

As family perceptions and experiences of ICU care can vary based on whether the patient survives to discharge,²⁶ we conducted a sensitivity analysis stratifying each outcome by survival. As in statistical analysis of the total group, we assessed prevalence and risk factors for each outcome within survivors and nonsurvivors and tested for between-group differences. Multivariable models for lack of control were created separately for survivors and nonsurvivors.

RESULTS

Of about 3,500 family members asked to participate in the FS-ICU survey, 1,559 surveys were returned—766 out of about 800 families of survivors (exact number unknown), and 793 out of 2,714 families of nonsurvivors. Fifty-two percent of respondents were the spouse of the patient and 29.9% were the adult child of the patient. Respondents were 71.2% female and had a mean age of 59.3 years (Table 1).

The mean age of the patients was 68.3 years, and 43.4% were female; 68.6% were mechanically ventilated and 42.8% received vasopressors; 50.7% died. These represent a group of patients more ill than our average ICU population during this time (10.4% mortality) in large part because of our sampling strategy, which allowed for as many families of nonsurvivors to respond as families of survivors.

Prevalence and Risk Factors for Inadequate Respect

Respondent families reported inadequate respect for the patients 16.9% of the time (256/1,517; 42 missing) and inadequate respect for family 21.8% of the time (333/1,527; 32 missing). The patients whose family members reported inadequate respect for the patient did

not differ by gender, age, or race compared to those whose family members reported optimal respect. Family members reporting this harm were slightly younger (mean age 57 vs. 60; $p = 0.004$) and more likely to be the adult child of the patient (OR, 1.34; 95% CI = 1.01–1.79). Similarly, the patients whose family members reported inadequate respect for themselves did not differ by gender, age, or race compared to those whose family members reported optimal respect for the family. Respondents reporting this harm were slightly younger (mean age 57 vs. 60; $p = 0.003$) and more likely to be the adult child of the patient (OR, 1.38; 95% CI = 1.06–1.78).

Univariable (unadjusted) analysis of clinical factors showed no association between either inadequate respect for the patient (Figure 1a) or inadequate respect for the family member (Figure 1b) and the patient's primary diagnosis, number or type of comorbidities, ICU length of stay, type of primary service (medical vs. surgical), patient mental status, admission to a team with residents, number of radiology studies, number of procedures (including central lines), or need for life-support therapy, including mechanical ventilation, vasopressors, or initiation of dialysis.

Prevalence and Risk Factors of Lack of Control

The majority (57.3%) of respondents (856/1,495; 64 missing) reported they had poor control over the care their family member received. Patients whose family members reported lack of control did not differ by gender, age, or race from patients whose family members reported good control. Family members who reported lack of control did not differ by gender, age, or relationship to the patient. However, several clinical characteristics were significantly associated with lack of control over the care of a loved one. Variables included in our multivariable logistic regression model were those that were significant on univariate analysis and potential confounders of those univariate-outcome relationships (team staffed by residents, care by a primary medical ICU team, receiving life-support therapy, sex of patient, sex of proxy, type of relative). In both adjusted (for other covariates in the model) and unadjusted analysis, families reported higher levels of control when the patient was cared for by a primary medical ICU team (adjusted OR [AOR], 1.3; 95% CI = 1.1–1.7), or by a team staffed by residents (AOR, 1.6; 95% CI = 1.1–2.3), or if the patient received any life-support therapies—defined as use of either mechanical ventilation, vasopressors, or initiation of dialysis—(AOR, 1.6; 95% CI = 1.3–2.1) (Figure 2).

Most of the respondents (90.5%) reported having experienced at least one of the following: inadequate respect for the patient, inadequate respect for family, and/or lack of control (1,351/1,492; 67 missing); and 38.9% (580/1,492; 67 missing) reported experiencing all three of the above. All three experiences were tightly correlated with several other items on the FS-ICU, including overall satisfaction with care (Part 1, item 16) and agreement among family members (Part 2, item 13) regarding care received.

Survivors vs. Nonsurvivors

In subgroup analysis by survivorship, inadequate respect for the patient was more frequently reported by family members of nonsurvivors (19.4% family of nonsurvivors vs. 14.4% family of survivors; $p = 0.01$). Rates of reported inadequate respect for the family did not

differ by survival status (22.6% family of nonsurvivors vs. 21.1% family of survivors; $p = 0.50$). Family members of nonsurvivors were less likely to report a lack of control for their loved one (42.5% family of nonsurvivors vs. 67.8% family of survivors; $p < 0.001$).

The characteristics of patients and families with emotional harms differed between survivors and nonsurvivors. Being an adult child was associated with inadequate respect for the patient and inadequate respect for the family among survivors but not among nonsurvivors. The factors associated with a higher reported levels of control also differed by survivorship. Among survivors, the sense of control was associated with being on a medical service (AOR, 1.45; 95% CI = 1.06–1.98). By contrast, among nonsurvivors, only being on a team with residents was associated with sense of good control (AOR, 1.94; 95% CI = 1.09–3.5) (Figure 3).

DISCUSSION

We found that a large cohort of critically ill patients and their family members experienced inadequate respect during hospitalization for critical illness. About one fifth of family members reported a lack of respect toward the patient or themselves, and more than half reported a lack of control over the care of their loved one. By comparison, medication errors—a physical harm targeted by hospital safety initiatives—are reported to happen to about 5% of hospitalized patients.^{27,28} Several clinical factors from a patient's ICU course were associated with a family member's perception of lack of control, but none of these clinical factors were associated with family members reporting inadequate respect to either themselves or to the patient. On the other hand, family members reporting inadequate respect were more likely to fit a specific demographic—adult children of the patient—but there were no demographic differences between families who reported good control vs. lack of control. As the association between this demographic and the perception of inadequate respect was weak, the significance and generalizability of this finding are unknown. The absence of clear and convincing associations of covariates with perceptions of inadequate respect highlights the difficulties in predicting these occurrences.

We expected more clinical factors to be associated with disrespectful care. For example, we hypothesized that patients undergoing more frequent procedures might be at greater risk for feeling violated, or that patients with a maximum Richmond Agitation-Sedation score of 2 or greater may be at greater risk for any form of disrespectful care. However, neither was associated with inadequate respect. We found that family members of nonsurvivors more frequently reported inadequate respect for the patient but also reported higher levels of control. The latter finding may reflect the involvement of many families of nonsurvivors in shared decision making resulting in withdrawal of life-support therapies. The former finding was much more surprising, as it contrasts with prior literature demonstrating overall higher satisfaction among family members of nonsurvivors.²⁶ We considered this finding to be hypothesis-generating; some possible contributors to perceptions of inadequate respect may be related to moral distress around continuation of life-support therapies that in retrospect “did not work,” or to distress related to ultimate withdrawal of such life-support therapies. The contrast between this finding and prior literature emphasizes that perceptions of

inadequate respect may be more nuanced and difficult to predict than other emotional experiences.

We found that families of patients who received life-support therapies or were cared for by residents reported a higher sense of control over their loved one's care. The implementation of life-support therapies is ideally the product of shared decision making between physician and family, and that process (which often involves formal consent at the very least) may facilitate an increased sense of control. The latter association—between resident involvement and higher sense of control over care—may be in line with prior literature demonstrating improved quality and patient satisfaction on services with residents, as these teams tend to be larger and often include several levels of trainees, which serve as “checks and balances.”^{29(p. 394)} Further studies are necessary to characterize the effects of teams with trainees on family perceptions of control.

Notably, not all families viewed control over care uniformly. Although one family member stated in free-text response, “I had to put my foot down to feel like I had control over [my loved one's] care,” many others stated, “I didn't know what questions to ask and I didn't want any control,” “I shouldn't have any decisions—I don't have any knowledge,” and “I wanted [the care providers] to have all the control.” We therefore have not categorized “lack of control” as an emotional harm. Indeed, prior literature has noted that there is significant cultural variation in family member's preference for having decision-making control in the care of their loved ones,³⁰ and in such cases, discordance between a family member's actual decision-making role and preferred decision-making role led to a higher prevalence of post-intensive care syndrome.³¹

Our work has several important strengths. First, we used a well-developed and validated instrument, the FS-ICU, and collected data from a large cohort. Second, with a comprehensive ICU electronic health record, we were able to link survey responses to patient records and explore associations between our outcomes of interest and a comprehensive list of potential clinical and demographic risk factors. Third, we included both survivors and nonsurvivors. Prior studies have assessed dignity-related distress at the end of life (for example, using the Patient Dignity Inventory [PDI]).³² However, with rising ICU survivorship and the known lasting detrimental effects of harms to patient dignity beyond the ICU, it is essential that we understand risk factors to both survivors and nonsurvivors. Indeed, in our sensitivity analysis, it was only among family members of survivors that being the adult child of the patient was associated with reporting either inadequate respect for the patient or the family member.

Limitations

Our findings should be interpreted in the context of limitations. First, as a single-center study in a large academic tertiary care facility, our results may not be generalizable to other settings. However, our prevalence of emotional harms mirrors the findings of the original multicenter FS-ICU validation study, in which estimates of inadequate respect varied between 19% and 47% for the patient and 29% and 63% for the family member, across multiple centers.¹⁷ Second, the FS-ICU was initially validated to determine family satisfaction and was not specifically intended for quantifying prevalence of emotional harms.

However, single items and subscales of the FS-ICU have been successfully used in prior literature to assess family views of other important aspects of ICU care, including decision making,³³ spiritual care,³⁴ and physician competence.²¹ Until recently, there had not been a validated instrument to measure respect and dignity in the critical care setting. The recently published ICU-RESPECT index could be used in the future to confirm our findings.³⁵ Third, the specific survey item used to measure respect actually measures “courtesy, respect, and compassion” shown toward either the patient or the family member. As this was a composite item, it is possible that the outcome represents emotional harms other than inadequate respect. However, Sokol-Hessner et al. define *respect* as “the sum of the actions we take to protect, preserve and enhance the dignity of our patients,”^{11(p. 551)} and it is our view that the ability to show courtesy and compassion stems from respect for the patient as a person. We therefore believed it reasonable that this survey item represented inadequate respect in its various representations. Fourth, family members could be approached only during working business hours because of interviewer availability constraints. However, the timing (delay of survey for families of nonsurvivors) and approach to inviting families of survivors to participate paralleled the timing and approach in the development and validation of the FS-ICU instrument.¹⁸ Furthermore, in at least one study, proxies enrolled during daytime hours did not differ significantly from those who could be enrolled on evenings and weekends.³⁶ Finally, despite the breadth of clinical information available to us, there are other risk factors for inadequately respectful care that deserve further investigation, including socioeconomic status (such as maximum education level and income), gender identity and sexual orientation, and issues surrounding negotiated death and cessation of life support.

CONCLUSION

Emotional harms to critically ill patients and their families have largely gone unrecognized and unmeasured. However, emotional harms can be as long-standing and troubling as physical harms, not only for the growing population of ICU survivors but also for families of survivors and nonsurvivors. We demonstrated that emotional harms are prevalent but remain difficult to predict from patient, family, and clinical characteristics. These results serve as a catalyst for future studies that incorporate different approaches for capturing such harms and evaluating their preventability.

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Figure 1:

Univariable analysis shows no association between either inadequate respect for the patient (Figure 1a) or inadequate respect for the family member (Figure 1b) and clinical factors. Adult children of patients are more likely to report both inadequate respect for the patient (odds ratio [OR], 1.34; 95% confidence interval [CI] = 1.01–1.79) and inadequate respect for the family member (OR, 1.38; 95% CI = 1.06–1.78). Black squares represent ORs; error bars represent 95% CIs. RAS, Richmond Agitation-Sedation Scale; pt, patient.

Figure 2:

Families reported higher levels of control when the patient was cared for by a primary medical ICU team (adjusted odds ratio [AOR], 1.3; 95% confidence interval [CI] = 1.1–1.7) or by a team staffed by residents (AOR, 1.6; 95% CI = 1.12–2.3), or if the patient received any life-support therapies—defined as use of either mechanical ventilation, vasopressors, or initiation of dialysis—(AOR, 1.6, 95% CI 1.3–2.1). Odds ratios are adjusted for other variables presented as well as for sex of patient and proxy, and type of relative. Black squares represent AORs; error bars represent 95% CIs.

Figure 3:

Inadequate respect for the patient was more frequently reported by family members of nonsurvivors (19.4% family of nonsurvivors vs. 14.4% family of survivors; $p = 0.01$). Rates of reported inadequate respect for the family did not differ by survival status (22.6% family of nonsurvivors vs. 21.1% family of survivors; $p = 0.50$). Family members of nonsurvivors were less likely to report a lack of control for their loved one (42.5% family of nonsurvivors vs. 67.8% family of survivors; $p < 0.001$). Black squares represent adjusted odds ratios; error bars represent 95% confidence intervals

Table 1.

Characteristics of ICU Patients and Family Members Responding to the FS-ICU Survey

Patient Characteristics (<i>n</i> = 1,559)	
Female sex, no. (%)	676 (43.4)
Age, mean (SD)	68.3 (16.9)
Race, no. (%) [*]	
White	717 (84.5)
Black	61 (7.2)
Other	71 (8.4)
Ventilated, No. (%)	1,069 (68.6)
Vasopressors, No. (%)	667 (42.8)
ICU LOS 4 days, no. (%)	802 (51.4)
Family Member Characteristics (<i>n</i> = 1,559)	
Female sex, no. (%)	1,110 (71.2)
Age, mean (SD)	59.3 (14.1)
Relationship to patient, no. (%) [†]	
Spouse	801 (52.0)
Parent	92 (6.0)
Sibling	89 (5.8)
Child	461 (29.9)
Other	97 (6.3)

^{*} Out of 849 patients for whom race was documented in medical record.

[†] Out of 1,540 respondents who reported relationship to patient. SD, standard deviation; LOS, length of stay.