

Effect of Palliative Care-Led Meetings for Families of Patients with Chronic Critical Illness: A Randomized Clinical Trial

Take Away Points

- Compared with usual care, the use of palliative care-led informational and emotional support meetings did not reduce anxiety or depression for family caregivers of patients with chronic critical illness and may have increased posttraumatic stress disorder symptoms.
- The study's findings do not support routine or mandatory palliative care-led discussion of goals of care for all families of patients with chronic critical illness.

The Issue

Patients are considered to have developed chronic critical illness when they experience acute illness requiring prolonged mechanical ventilation or other life-sustaining therapies but neither recover nor die within weeks. These patients often have limited one-year survival and require institutional care after hospital discharge. It is estimated that chronic critical illness affected 380,000 patients in the United States in 2009, accounting for health-related costs of \$35 billion or 1.4% of annual US health care costs.

Source

Carson SS, Cox CE, Wallenstein S, et al. (2016). Effect of palliative care-led meetings for families of patients with chronic critical illness: a randomized clinical trial. *JAMA*. <http://jama.jamanetwork.com.ezproxy.uky.edu/article.aspx?articleid=2532011>

Family members of patients in the intensive care unit (ICU) often experience emotional distress including anxiety, depression, and posttraumatic stress disorder (PTSD). Communication regarding expected outcomes of patients is often inadequate to support surrogate decision making about goals of care and expectations. Interventions involving palliative care specialists are potentially important in addressing these issues, as they are trained to provide emotional support, share information, and engage patients and surrogate decision makers in discussions of patients' values and goals of care.

The objective of this trial was to evaluate the relative effectiveness of a palliative care specialist-led communication intervention in improving family and patient-centered outcomes for families of patients with chronic critical illness. The study's primary outcome was symptom score of anxiety and depression in family caregivers three months post-intervention.

Study Methods and Design

A multicenter randomized clinical trial was conducted from October 2010 through November 2014 in 4 medical intensive care units (ICUs) in different regions of the U.S. Adult patients (aged ≥ 21 years) requiring 7 days of mechanical ventilation who were not expected to be weaned or die within 72 hours were randomized. The family surrogate decision maker(s) of these patients were approached to participate in the study. Randomization to the intervention or control group occurred after enrollment with blinding of allocation.

- **Intervention:** Provision of a standardized, widely available brochure on chronic critical illness to family decision maker(s), along with a minimum of 2 structured informational and support-based family meetings led by a palliative care specialist.
- **Usual Care Control:** Provision of the identical informational brochure, with ICU specialists managing all formal and informal family meetings per their usual practice without input from palliative care specialists.

Outcome measures included:

- **Primary outcome-Hospital Anxiety and Depression Scale (HADS):** obtained at 90-day follow-up interviews with family surrogate decision makers [Score (0) is best to (42) worst]
- **Secondary outcomes-Posttraumatic stress disorder (PTSD)** symptoms of the family surrogate decision maker at 90 days measured by the Impact of Event Scale-Revised (IES-R) [Score (0) is best to (88) worst];
- **Other measures included- Patient-focused communication on goals of care:** assessed by 3 questions in an advance care planning domain from a modified version of the After-Death Bereavement Family Interview; **Quality of Communication** assessed after intervention; and, **Family Satisfaction** assessed at 90 days.
- **Patient-focused outcomes included-** number of ventilator days, ICU and hospital length of stay, limitations of ICU therapies, hospital mortality, 90-day survival.

Key Findings

- **Sample characteristics:** There were 130 patients with 184 family surrogate decision makers in the intervention group and 126 patients with 181 family surrogate decision makers in the control group. No significant baseline differences between patients in the intervention and control groups were detected, with the exception of slightly higher independence in activities of daily living in the intervention group. No significant differences were noted between groups in the demographics of family surrogate decision makers.
- **Anxiety and depression (primary outcome measure):** At 3 months, there was no significant difference in anxiety and depression symptoms between surrogate decision makers in the intervention and control groups (adjusted mean HADS score, 12.2 vs. 11.4, respectively; between-group difference, 0.8 [95% CI, -0.9 to 2.6]; $P=.34$). Adjusting for other characteristics (ex. study site, race, sex) did not significantly affect the difference.
- **PTSD (secondary outcome measure):** PTSD symptoms were *higher* in the intervention group (adjusted mean IES-R, 25.9) compared with the control group (adjusted mean IES-R score, 21.3) (between-group difference, 4.60 [95% CI, 0.01 to 9.10], $P=.0495$).
- **Patient-focused communication about goals of care:** Most family surrogate decision makers in both groups stated that medical treatments and procedures had been discussed and were consistent with the wishes of the patients. There also was no significant difference between groups in providing affirmative answers to all three preference questions (intervention 75%, control 83%; odds ratio, 0.63 [95% CI, 0.34 to 1.16; $P=.14$).
- **Length of hospital stay and Survival:** The median number of hospital days for patients in the intervention vs. the control group (19 days vs. 23 days, respectively; between-group difference, -4 days [95% CI, -6 to 3 days]; $P=.51$) and 90-day survival (hazard ratio, 0.95 [95% CI, 0.65 to 1.38], $P=.96$) were not significantly different.

Limitations: Although research personnel conducting the interviews were blinded to study group allocation, families participating in the intervention were not. There is also the possibility of control

group contamination since consults with the palliative care team were discretionary and could have biased the study toward the null.

Final Thoughts

Among families and patients with chronic critical illness, the use of palliative care specialist-led informational and emotional support meetings compared with usual care did not reduce anxiety or depressive symptoms among family surrogate decision makers and may have increased posttraumatic stress disorder symptoms. Patient outcomes, including duration of mechanical ventilation, hospital length of stay, and 90-day survival, also showed no benefit from the intervention relative to usual care. Multiple explanations for this lack of benefit are plausible, including that the length and intensity of the intervention were insufficient to overcome high levels of stress. These results indicate that decision-making about continued intensive care for patients with chronic critical illness may present greater challenges for successful interventions. Based on these findings, the use of routine specialist palliative care in patient population with chronic critical illness may be ineffective if the interaction is limited to only 1 to 2 meetings.