Family Satisfaction with Communication and Shared Decision Making in Neuroscience Intensive Care Units: Room for Improvement

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Introduction

Because most brain-injured patients in neuroscience intensive care units (NICUs) do not possess decision-making capacity, NICU clinicians often rely on their families as surrogates for making important shared decisions about their care. While studies assessing family satisfaction with provider communication and shared decision making processes in general critical care units have become increasingly common, little is known about how families perceive such crucial elements of care in ICUs that specialize in neuroscience. To identify areas where communication between NICU providers and families could be improved, we surveyed families of patients in an academic NICU regarding their satisfaction with aspects of shared decision making and their interactions with care providers.

Methods

This single-NICU survey study was conducted prospectively from December 2012 to September 2014. For each patient (1) who survived a NICU admission of longer than 3 days or (2) whose goals of care were changed to comfort measures only (CMO) during a NICU admission, we sought to enroll one family member in this study, with priority given to the recruitment of the healthcare proxy of an eligible patient wherever possible. Family members of CMO patients were mailed paper surveys one month after death or NICU discharge, while all other family members took the survey in the hospital either 24 hours before patient transfer to the floor or within 48 hours after transfer. The survey administered was the FS-ICU 24, an extensively validated questionnaire that asks respondents to rate satisfaction with specific aspects of ICU care using Likert scales, with a specific focus on elements of shared decision making. Relevant demographic information for all survey respondents and clinical data for all patients whose families were enrolled were also collected. We analyzed responses to FS-ICU items using descriptive statistics for top-box responses, similar to how standard CAHPS Hospital Survey results are often reported.

Results

During the study period, we enrolled 148 of a possible 284 (52.1%) eligible family members of NICU patients. Of those surveyed, only 64.4% (85 out of 132 respondents answering the item) reported complete satisfaction with the frequency of communication from nurses about their relative’s clinical condition. A smaller proportion of families (82/137, 59.9%) were completely satisfied with the frequency of communication from NICU physicians. When patient information regarding clinical condition was provided to families by multiple NICU care providers, 64.3% (90/140) of families were completely satisfied with the consistency of that information. Only 63.2% (91/144) of families were completely satisfied with the emotional support provided by NICU staff. Finally, 65.7% (94/143) of families felt “very included” in the processes of shared decision making, while 52.1% (74/142) felt “very supported” by the ICU staff during such processes.

Implications

There is significant opportunity with regards to improving family satisfaction with crucial aspects of provider communication and shared decision making in NICUs. Targeted interventions to improve frequency of communication, consistency of information provided, emotional support, and inclusion in and support for shared decision making have the potential to improve the experience of patients’ families in NICUs in the future.