A qualitative investigation of communication between pediatric critical care providers and patient's parents or guardians.

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Introduction

Effective communication of clear and appropriate medical information between parents and guardians and the provider teams is crucial for the families' understanding of the child's disease process, goals of care and ultimate prognosis. Unclear communication can lead to misunderstanding and compromise care. Prior work over the past two years by this group has improved Hospital Consumer Assessment of Healthcare Providers and Systems (Press-Ganey) patient satisfaction scores by over 5% and resulted in changes in how rounds were conducted and led to the greater use of interpreters during patient rounds. However, we still were uncertain of what families perceived as obstacles to effective communication in the PICU, and if the barriers perceived by families might be different than those perceived by providers.

Objective

To characterize the perspective of parents and guardians of critically ill children regarding communication with healthcare providers.

Methods

We conducted semi-structured interviews of 41 parents and guardians of children who were admitted to a tertiary pediatric intensive care unit in 2017. The interview structure was specifically designed to uncover any deficits in communication between the families and providers. Open ended questions such as, “how could things have gone better”, were used to delve into this. Each of the interviews was audio-recorded and professionally transcribed verbatim. An interprofessional team of a Pediatric Critical Care Fellow, nurse manager, and medical student then separately coded each of the transcripts. The resultant codes were organized into common themes using the constant comparative method. The interviewing process continued until thematic saturation was reached.

Results

The families interviewed represented 16 acutely ill children with minimal past medical history and 25 children with chronic health conditions. Patient ranged in age from 11 days to 18 years old. Twenty families self-identified as Caucasian, 8 as Latino, 6 as African-American, 6 as Asian Pacific Islander, and 1 as Middle Eastern. Length of PICU stay ranged from 24 hours to 4 months, and number of past PICU admissions ranged from 0 to more than 10. Perceived communication deficiencies between health care providers and families included: 1) feeling that their child was discharged from the PICU before the child was ready, 2) not receiving care updates if they were not present for rounds, 3) lack of communication/coordination between specialty services, 4) suboptimal communication was more common at night, 5) among parents of children with long-term chronic health conditions, their opinions were not felt to be valued.

Implications

Communication between families and health care providers is a key component of the family's experience during their child's critical illness. Families perceived communication barriers can negatively impact the PICU experience and the child's health. Eliminating these perceived barriers would improve the overall patient experience and health outcomes. The use of the qualitative interview survey method revealed deficits that had not been evident in simple surveys such as the Hospital Consumer Assessment of Healthcare Providers and Systems.