Identifying Social and Clinical Influences on Pediatric End-of-Life Care in the PICU

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<u>Abstract</u>

Background: The majority of pediatric deaths occur in intensive care settings. Little is known about whether end-of-life (EOL) care in the pediatric intensive care unit (PICU) varies based on sociodemographic or clinical factors.

Objective: Identify social and clinical characteristics associated with specific EOL care descriptors among PICU decedents.

Methods: Retrospective chart review of patients at an academic tertiary care children's hospital in Chicago, IL who died in the PICU between January 2011 - December 2016. Sociodemographic and clinical data were collected from the electronic health record. Five descriptors of EOL care were assessed: withdrawal/withholding of life-sustaining treatment (WOLST), palliative care (PC) consultation, Do Not Attempt Resuscitation (DNAR) orders, documented care conferences (DCCs), and opioid administration \leq 24 hours before death. Descriptive statistics and Chi-squared analysis were used.

Results: Over six years, there were 11,527 PICU admissions and 263 deaths (2.3%). Decedents were between 0 days to 25 years old, predominantly male (59%), white (35%), English-speaking (82%), with public insurance (60%). Overall, 67% of patients died after WOLST, and an equal percentage had a DNAR order in place with 85% concordance. There were no significant differences between racial/ethnic groups for any EOL care descriptors apart from DCCs, which were more common for black (62%), Latino (68%), and other (72%) patients compared to white patients (46%) (p = .006). Non-English speakers were more likely than English speakers to have PC consultation (58% vs 42%, p = .04), DCCs (77% vs 56%, p = .007), and DNAR orders (79% vs 64%, p = .04). Among the 45% of patients who received a PC consult, there were significantly higher rates of DCCs (79% vs 44%, p < .001), DNAR orders (84% vs 52%, p < .001), opioids before death (95% vs 76%, p < .001), and WOLST (82% vs 53%, p < .001). Oncology patients were more likely than non-oncology patients to have PC consultation (66% vs 40%, p < .001), DNAR orders (79% vs 63%, p = .03), and WOLST (82% vs 63%, p = .004).

Conclusion: Sociodemographic and clinical characteristics of PICU patients are associated with distinct patterns of EOL care. Racial/ethnic differences were only observed in rates of DCCs. Care conferences, DNAR orders, and PC support may be utilized to address communication challenges in non-English speaking patients. PC consultation is associated with DCCs, DNAR orders, opioids before death, and WOLST.