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Assessing Staff Perspective in Providing End-of-Life Care to Pediatric Patients

When providing end-of-life (EOL) care to pediatric pediatrics, multidisciplinary staff collaborate to mitigate suffering and provide support for patients and families. The shared goal is to provide a "good death," defined by the National Academy of Medicine as "free from avoidable distress and suffering, for patients, families, and caregivers; in general accord with the patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards." A needs assessment was conducted to learn about staff experience and perspective while caring for pediatric patients at the EOL.

An online, cross-sectional survey was developed and distributed to eligible staff members within one week of all patient deaths at our free-standing children's hospital and local hospital-affiliated pediatric emergency departments from January to June 2023. Staff were deemed eligible if they provided EOL care, indicated by documentation in the electronic medical record, within the final 24 hours of the patient's life. Survey domains included staff discipline and location, support services involved, characteristics of the patient and family's EOL experience, and staff's comfort, experience, and training in providing EOL care. Data was managed and stored within REDCap.

69 of 169 eligible staff members (41% response rate), representing 19 patients, completed the survey. Most were physicians (44%) working in the pediatric intensive care unit (51%). More than half (54%) of staff members felt their patient's death was sudden or unexpected. Approximately 7% disagreed that the child was comfortable at the EOL, and 1 in 4 disagreed that the child's death was a "good death." Nearly half of staff (48%) reported previous training in pediatric EOL or palliative care. Most (84%) reported having prior experience providing EOL care with 41% providing EOL care to more than 10 patients per year. Staff reported feeling well-supported (66%) and somewhat, very, or extremely comfortable providing EOL care to actively dying patients (91%), assessing the psychosocial needs of the patient's parents (90%), and discussing death with their patients (75%). Almost 1 in 4 (22%) staff members reported not feeling comfortable administering opioids at EOL.

There are opportunities for improvement in patient comfort at the EOL, formal staff EOL training, and staff comfort in providing EOL care, particularly with opioid administration. It is important that we learn more about the characteristics of a "good death" according to staff perspective in order to improve EOL patient care, increase family support, and reduce staff distress.