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

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Background

- Multidisciplinary staff collaborate to mitigate suffering and provide support for patients & families at end-of-life (EOL).
- The shared goal is to provide a "good death" as defined by the National Academy of Medicine (Figure 1).
- A needs assessment was conducted to learn about staff experience and perspective while caring for pediatric patients at the EOL.

Good Death

"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."

Figure 1. The National Academy of Medicine's definition of a "good death."

Methods

- An online, cross-sectional survey was developed and electronically distributed to eligible staff members (Figure 2) within one week of all patient deaths at our free-standing children's hospital as well as local hospital-affiliated pediatric emergency departments from January - June 2023.
- Data (Figure 3) was managed and stored in REDCap.

Eligible Participants

staff who provided EOL care, indicated by documentation in the electronic medical record, within the final 24 hours of the patient's life

Figure 2. Eligibility criteria for survey participation.

Staff Discipline	Staff Location	Support Services Involved	Perception of the Patient and Family's EOL Experience	Staff's Comfort, Experience, and Training in Providing EOL Care

• Advanced Practice Nurse
• Child Life Specialist (CLS)
• Physician Assistant
• Physician
• Registered Nurse (RN)
• Respiratory Therapist (RT)
• Social Worker (SW)
• Other
	• Cardiac Intensive Care Unit (CICU)
	• Emergency Department (ED)
	• Inpatient/Acute Care floor
	• Neonatal Intensive Care Unit (NICU)
	• Pediatric Intensive Care Unit (PICU)
	• Other
		• Chaplain
		• CLS
		• Integrative Therapy
		• Music therapy
		• Occupational therapy
		• Palliative Care
		• Physical therapy
		• Psychiatry
		• Psychology
		• Speech therapy
		• SW
		• Other
			• Child's comfort at EOL
			• Suddenness of death
			• Was the child's death considered a "good death"?
			• Parent and sibling support
				• Comfort in the following areas:
				  • providing EOL care
				  • giving opioids to patients in severe pain at EOL
				  • talking with pediatric patients about death and/or dying
				  • assessing psychosocial needs of parents
				• Prior experience and/or training in EOL care
				• Perception of staff support

Figure 3. Survey domains.

Results

- 69 of 169 eligible staff members (41% response rate), representing 19 patients, completed the survey. Most were physicians (Figure 4) and in the PICU (Figure 5).
- **Most (84%) reported having prior experience providing EOL care with 41% providing EOL care to more than 10 patients per year (Figure 6).**
- **Half of staff (48%) reported previous training in pediatric EOL or palliative care.**
- More than half of staff felt their patient's death was sudden or unexpected.
- **Few disagreed that the child was comfortable at EOL, and 1 in 4 disagreed that the child's death was a "good death"** (Figure 7).
- Staff felt parents were well-supported but were unsure about sibling support (Figure 8).
- Staff reported feeling well-supported and comfortable providing EOL care to actively dying patients, discussing death with their patients, and assessing psychosocial needs of parents (Figures 9A-C).
- **Almost 1 in 4 staff members reported not feeling comfortable administering opioids at EOL (Figure 9D).**

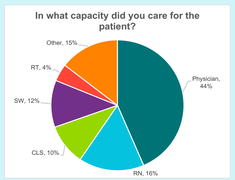


Figure 4. Staff discipline.

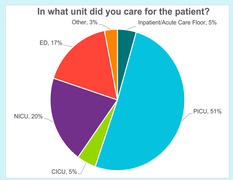


Figure 5. Staff location.

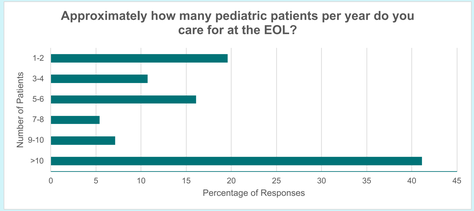


Figure 6. Staff experience with EOL care provision.

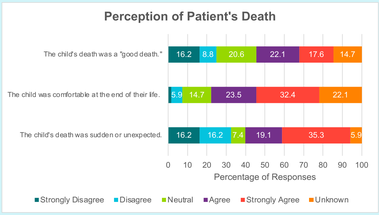


Figure 7. Staff perception of patient's death.

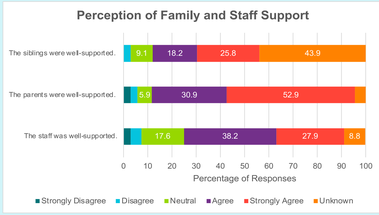
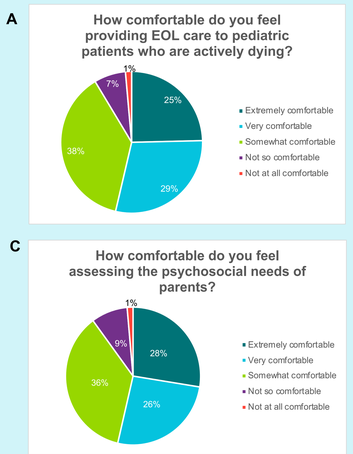


Figure 8. Staff perception of family & staff support at EOL.



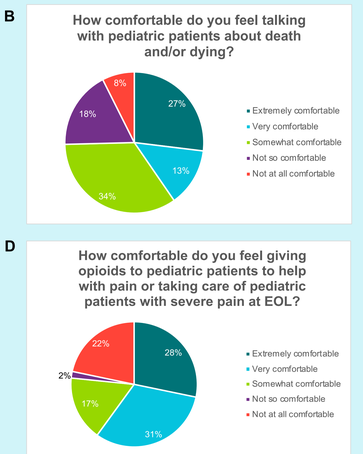


Figure 9. Staff comfort levels with EOL care provision.

Conclusions

- 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.
- Further studies are also needed to assess differences in staff's EOL experience within various hospital units and subspecialties.

Authors have no financial relationships to disclose.