

# A Bottom-Up Approach in Pediatric Ethics Education: Residents Leading Ethics Curriculum Development – A Pilot Project

## Curriculum Development – A Pilot Project



Allison Lyle, MD, MA,<sup>2,4</sup> Sarah Ali,<sup>1</sup> Zeynep Salih, MD, MA<sup>2,3,4</sup>

Indiana University-Purdue University Indianapolis, Department of Pediatrics, Division of Neonatology, Indiana University School of Medicine



### Background

- Pediatrics residents routinely face ethical dilemmas and moral distress during their training.
- There is no universal formal ethics curriculum for pediatric residents.
- Historically, ethics curricula have followed a top-down structure of didactic lectures instead of a bottom-up approach with residents self-identifying educational needs.
- Few studies have shown meaningful methods in reducing resident moral distress.

### Objectives

- To determine how resident-identified ethics case discussions are perceived by pediatric residents
- To determine whether such a program affects ethics knowledge and perceived moral distress

### Methods

- All pediatric and pediatric-combined residents in a mid-sized Midwest program were invited.
- Five cases were identified by residents and developed under the guidance of an ethicist.
- Cases were presented at 1-hour sessions over a 5-month period. Multidisciplinary services (e.g. department of child services, risk management) as well as content experts were invited.
- A baseline and finale survey was distributed to measure moral distress, perceived ethics importance and ethics knowledge.
- At the end of each session, a survey asking perceived benefits of the case discussion was distributed.
- Open-ended responses for session improvement were also solicited and stored securely in RedCap.

### Results

Question	Baseline Pre-Test (N=38)		Finale (N=18)		P
	Mean	Standard Deviation (SD)	Mean	Standard Deviation (SD)	
Please select the number (0-10) on the Moral Distress Thermometer (image) that best describes how much moral distress you have been experiencing related to work over the past 3 months.	8.290	1.395	7.444	1.756	0.081

Table 1: Moral Distress Scale- Baseline Pre-(before five case series) vs Finale (after five case series)

Question	Baseline Pre-Test (N=38)		Finale (N=18)		P
	Mean	Standard Deviation (SD)	Mean	Standard Deviation (SD)	
I encounter ethical decisions in my daily practice (Likert 1-5)	3.290	0.938	3.722	0.895	0.128
I feel prepared to deal with ethical decision in my practice (Likert 1-5)	3.226	0.845	3.889	0.471	0.004
I find that ethics discussions can increase and/or decrease my moral distress (Likert 1-5)	3.774	0.805	4.111	0.900	0.089
An understanding of ethics is important to my practice. (Likert 1-5)	4.516	0.508	4.722	0.461	0.165

Table 2: Perceived Importance of Ethics and Decision Making- Baseline Pre-(before five case series) vs Finale (after five case series)

No.	Question	Baseline Pre-Test		Finale		P
		% Correct	% Correct	% Correct	% Correct	
1	Sending an email to another clinician about a patient you both provide care to.	12(38.7%)	6(33.3%)	0.767		
2	Faxing a prescription to a pharmacy with the patient's name and date of birth clearly marked.	21(67.7%)	13(72.2%)	1.000		
3	A 16-year-old patient who is financially independent and lives apart from parents.	24(77.4%)	16(88.9%)	0.454		
4	A 15-year-old who is judged by his physician to have mature decision-making capacity.	29(93.5%)	17(94.4%)	1.000		
5	The information should not be disclosed because of the risk of social harm or stigmatization.	31(100.0%)	18(100.0%)	1.000		
6	This information should be disclosed to the baby's parents if the parents have participated in previous counseling and have given consent.	24(77.4%)	12(66.7%)	0.508		
7	The mother of a 5-year-old requests that her daughter be tested for the genetic mutation causing Huntington disease. The mother is a carrier of Huntington disease and wants to know if her child is affected.	19(61.3%)	12(66.7%)	0.767		
8	After meeting with a genetic counselor, the mother of a 5-year-old requests that her daughter be tested for the genetic mutation causing Huntington disease. The mother is a carrier of Huntington disease and wants to know if her child is affected.	2(6.5%)	2(11.1%)	0.618		
9	The mother of a 17-year-old requests that her daughter be tested for the genetic mutation causing Huntington disease. The mother is a carrier of Huntington disease and wants to know if her child is affected. The 17-year-old patient tells you that she does not want to be tested.	30(96.8%)	18(100.0%)	1.000		
10	These decisions should be altered in the delivery room and in the perinatal period if the neonate's condition at birth is much different than was expected prenatally.	25(80.6%)	17(94.4%)	0.238		
11	These decisions must involve consultation with the hospital legal team.	29(93.5%)	17(94.4%)	1.000		
12	These decisions depend on the projected benefits and burdens of the treatment as evaluated by the medical team and the parents.	29(93.5%)	18(100.0%)	0.526		
13	These decisions should generally involve consultation with the hospital's ethics service.	20(64.5%)	14(77.8%)	0.521		
14	The parents of a 10-year-old boy would like to use an alarm system to treat the patient's nocturnal enuresis. The patient does not want the alarm and will not give his assent to the proposed treatment.	7(22.6%)	5(27.8%)	0.738		
15	A 16-year-old sexually active female with a vaginal discharge gives informed consent for a pelvic examination without involvement of her parents.	31(100.0%)	18(100.0%)	1.000		
16	A 4-month-old is in need of routine childhood immunizations, but his parents refuse permission for the injections.	19(61.3%)	16(88.9%)	0.052		
17	Medically provided fluids and nutrition constitute a medical intervention that may be withheld or withdrawn for the same reasons that justify the medical withholding or withdrawing of other medical treatments.	29(93.5%)	16(88.9%)	0.618		
18	A 16-year-old with cystic fibrosis is refusing intubation in the setting of respiratory failure. Her informed decision to refuse further life-sustaining medical treatment ought to be respected.	23(74.2%)	13(72.2%)	1.000		
19	In order to relieve a child's severe and progressive symptoms related to refractory metastatic cancer, large doses of analgesics and sedatives are required. In this situation, the medications may be administered to the extent needed to ensure comfort, even if they cause the patient to become obtunded.	30(96.8%)	18(100.0%)	1.000		
20	There are fundamental ethical distinctions between deciding not to start a life sustaining treatment (such as a mechanical ventilator) and deciding to stop a life sustaining treatment that has already been started.	11(35.5%)	10(55.6%)	0.234		
21	A 5-year-old boy has sustained major head trauma. He is unaware of himself and his environment. His physicians diagnose him with persistent vegetative state. In this situation, the patient's enteral nutrition (administered via gastrostomy tube) may be ethically withdrawn.	25(80.6%)	16(88.9%)	0.693		
22	A physician is ethically justified in allowing a 15-year-old patient diagnosed with Chlamydia to give consent to antibiotic therapy without involving a parent or guardian.	27(87.1%)	17(94.4%)	0.639		
23	A parent's agreement to provide treatment to a child should be called "informed permission," not "informed consent."	11(35.5%)	8(44.4%)	0.559		

Table 3: Ethics Knowledge from Baseline Pre-Test to Finale

Question	Yes N(%)	No N(%)
This session was relevant to my practice	85(98.8%)	1(1.2%)
As a result of this session, I feel better prepared to address ethical concerns in my practice.	78(90.7%)	8(9.3%)

Table 4: Perceived Satisfaction and Perceived Preparedness (aggregate responses for the survey given after each five sessions)

### Discussion

- When comparing baseline and finale responses (Table 1), the only significance was increased preparedness to navigate ethical decisions (p=0.004).
- While not significant, a 10.2% decline was observed in resident moral distress.
- An increase in ethics knowledge was observed but was not significant (Table 2).
- Questions related to assent, HIPAA, and genetic testing were scored least correctly (Table 3).
- 85 free text submissions showed that residents favored the case-based discussions and multidisciplinary input. Residents expressed desire for more sessions, time for small group discussions and legal insight.
- Satisfaction was high overall with 90.7% of respondents feeling better prepared to address ethical concerns (Table 4).

### Conclusions

- Pediatric trainees face ethical dilemmas during training that cause moral distress.
- Residents feel that understanding ethics is relevant to their practice and ethics case discussions prepare them for making ethical decisions.
- While residents desire case-based ethical discussions, this format does not by itself decrease moral distress in this pilot study.

### References

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