Palliative Sedation in Pediatrics

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Disclosure

- I have no relevant financial disclosures.

Objectives

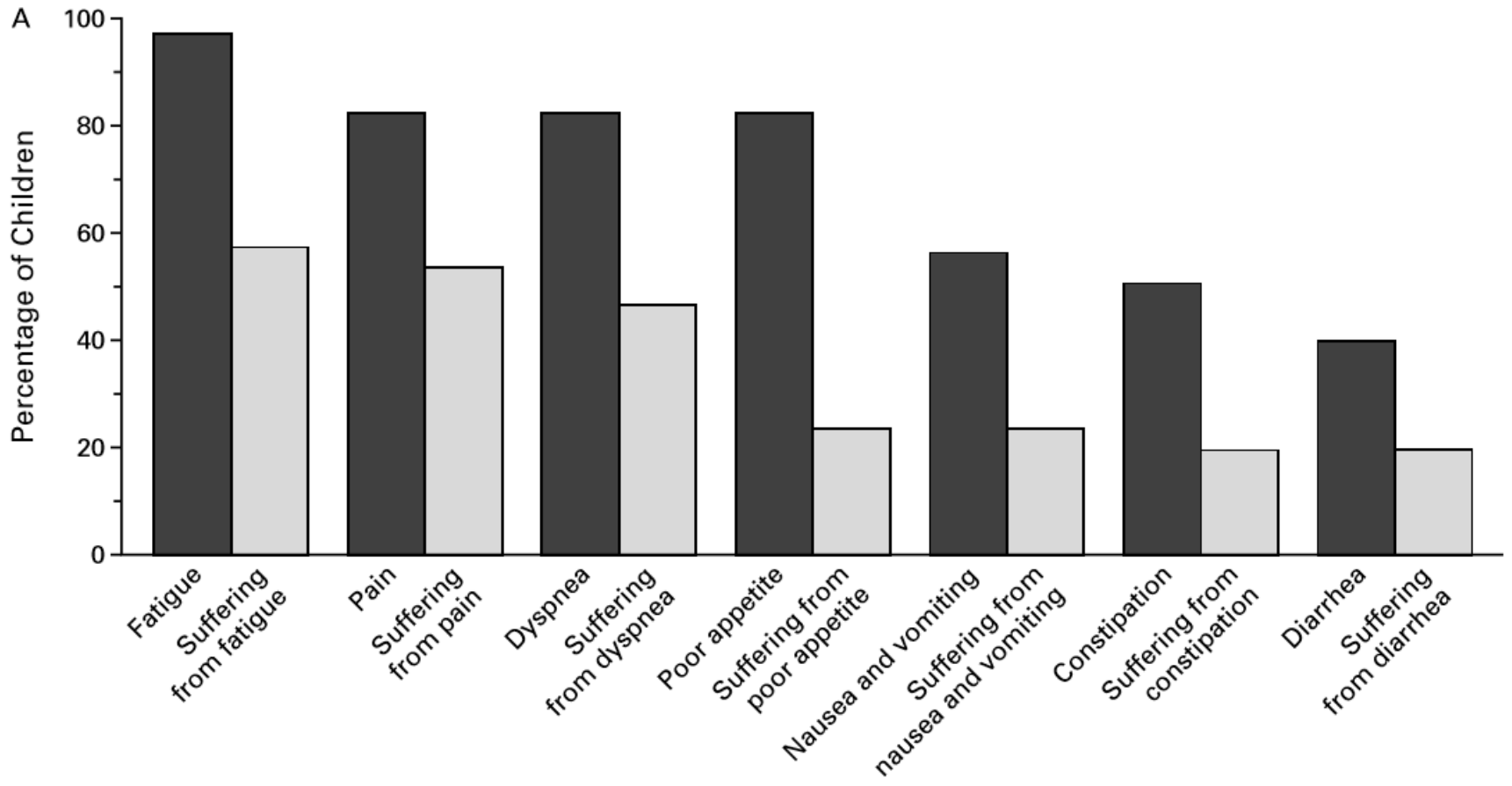
Upon completion of this activity, participants will be able to:

- Discuss the justification and ethical concerns about using palliative sedation for children.
- Identify strategies for resolving these cases that can guide policy development.

Neonates, Children and Adolescents

1. Children die.
2. We undertreat their symptoms when dying because #1.
3. Fear of dosing medications in children.

Suffering in Pediatrics



Wolfe, et al Symptoms and Suffering at end of life in children with cancer NEJM 2000

Medication exposure at end of life in children

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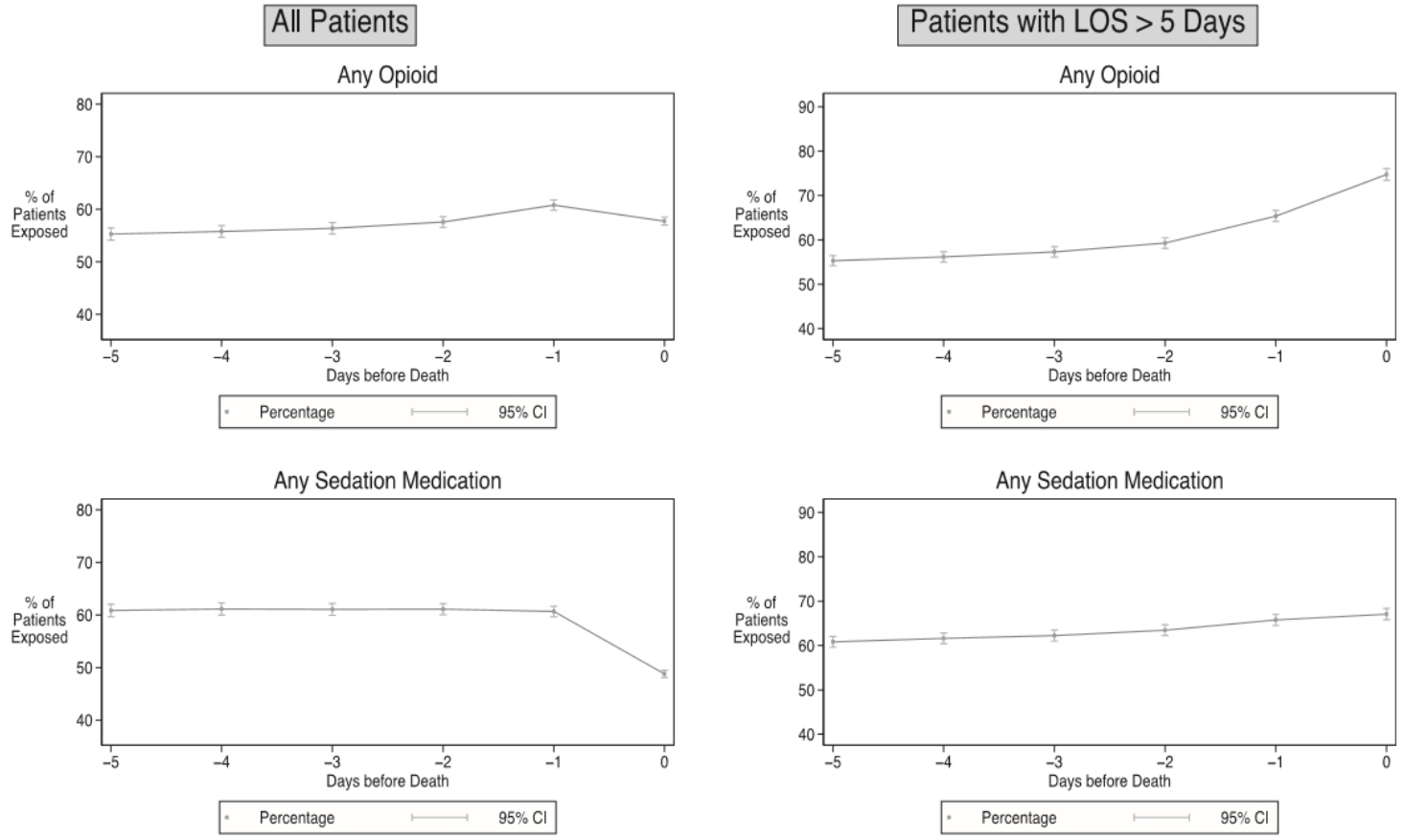
n=34,456



Pediatric Exposure to Opioid and Sedation Medications during Terminal Hospitalizations in the United States, 2007-2011

Lindsay Ragsdale, MD[1], Wenjun Zhong, PhD[2], Wynne Morrison, MD, MBE[2], David Munson, MD[2], Tammy I. Kang, MD, MSCE[2], Dingwei Dai, PhD[2], and Chris Feudtner, MD, PhD, MPH[2]

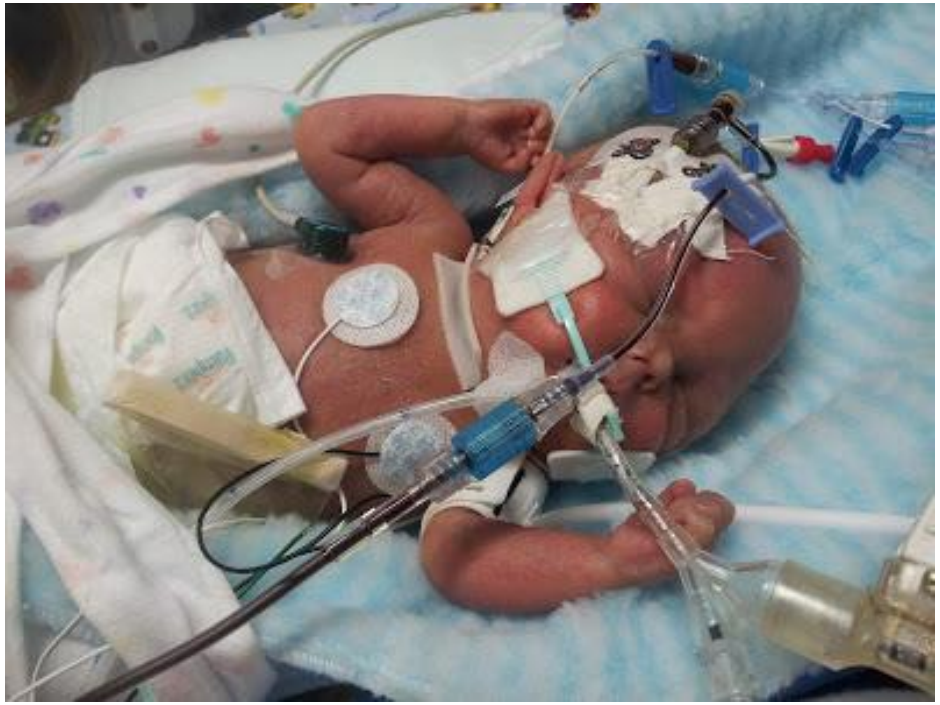
End of life care in pediatrics

- Most children die in the hospital
- Most involve withdrawal of life sustaining treatments
- Evolving practice to give medications for pain and suffering as standard approach

Palliative Sedation

- Neonatal:

6 week old baby girl on ventilator with airway anomaly.

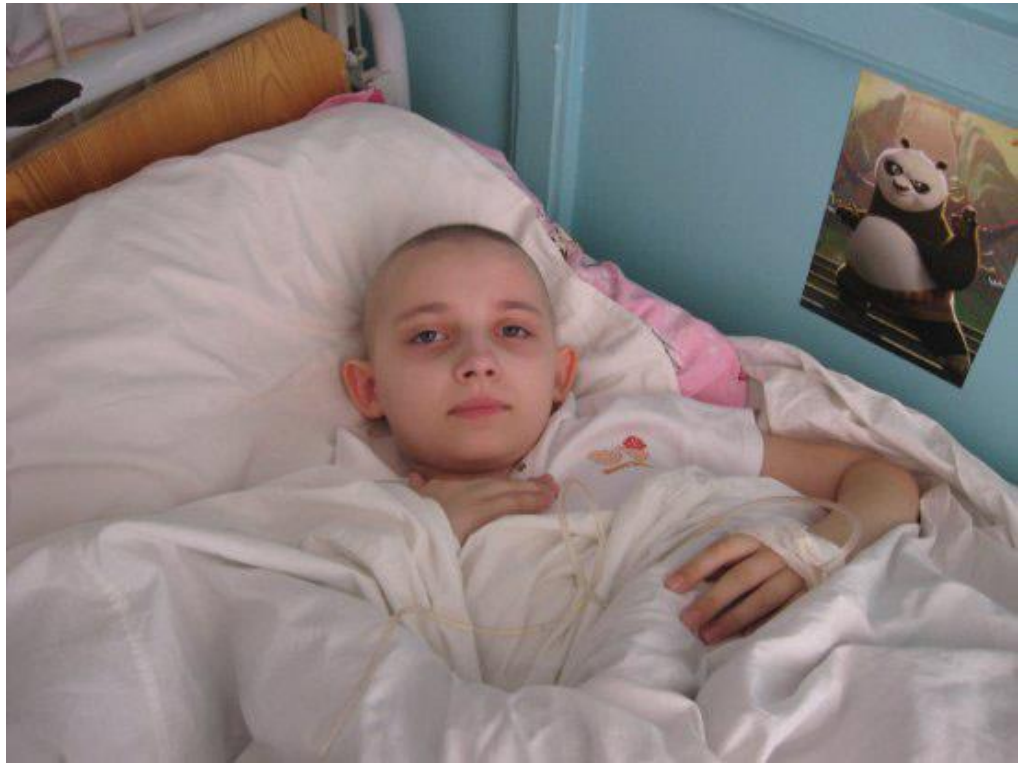


http://athreeecircus.blogspot.com/2012/06/baby-eagan-nicu-day-58-sepsis.html

Palliative Sedation

- Child:

10 year old with osteosarcoma for the past 7 years, now widely metastatic.



http://noxton.net/news4_en.html

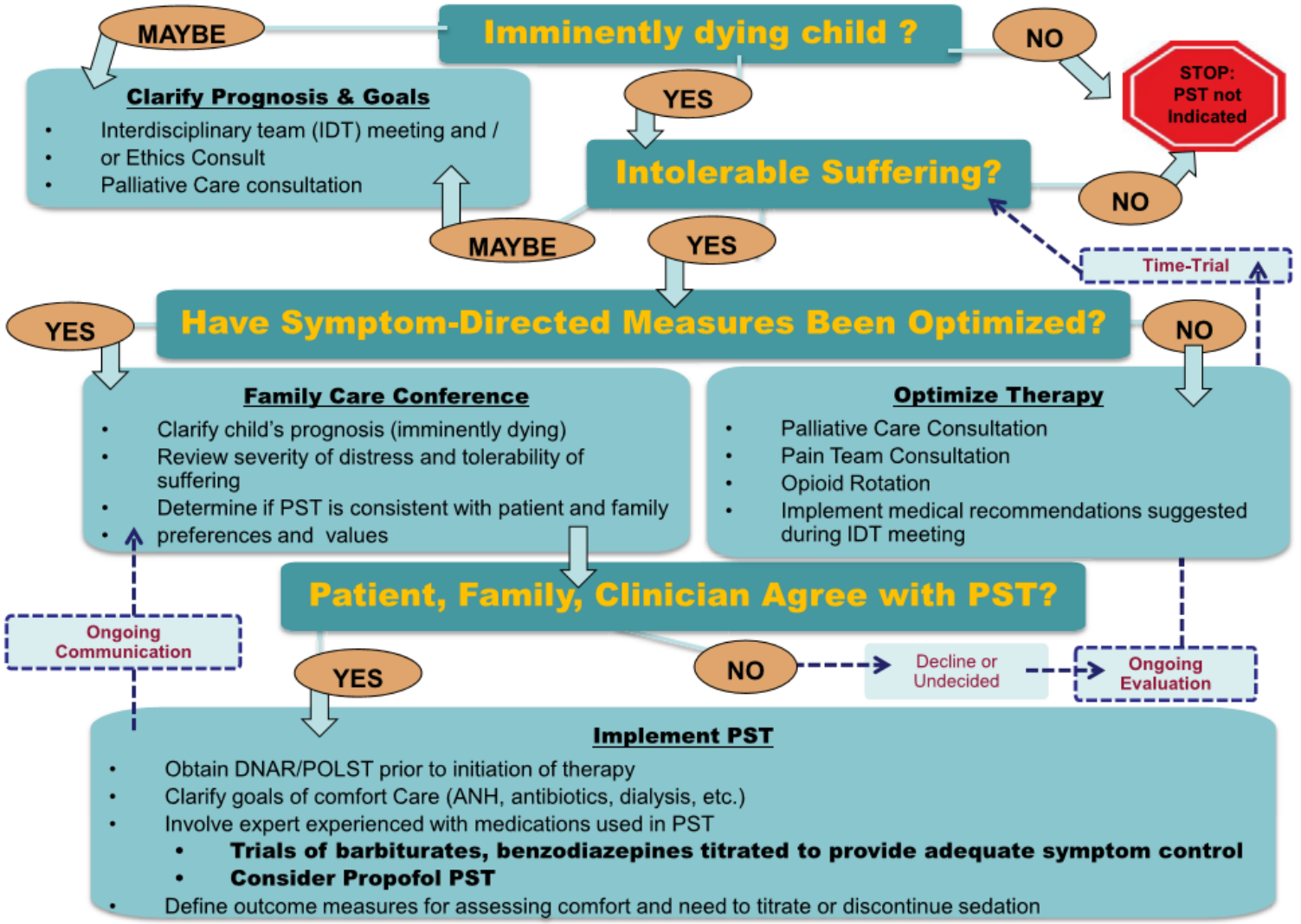
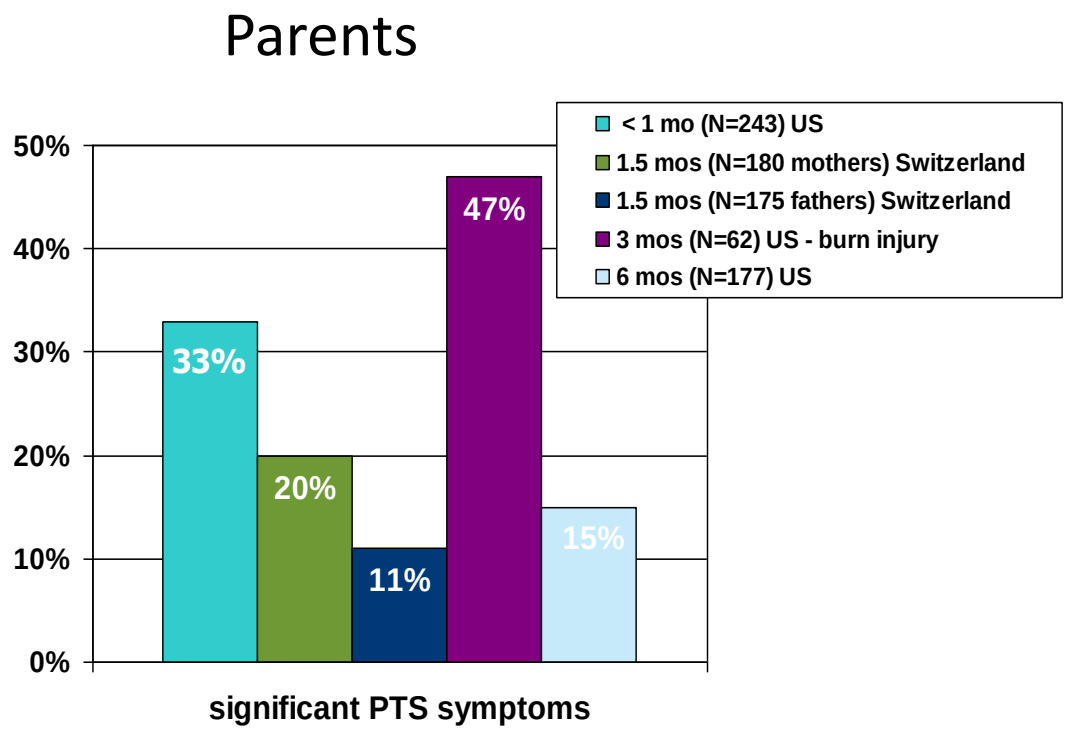


Fig. 2. Algorithm for initiation of palliative sedation. ANH, artificial nutrition and hydration; DNAR/POLST, do not attempt resuscitation/physician orders for life-sustaining treatment.

Palliative Sedation With Propofol for an Adolescent with DNR order
Johnson et al Pediatrics. 2017

Family distress

- High level of distress and trauma in family watching child suffering



Kahana et al. (2006), Landolt et al (2003), Fein et al. (2002)

Family Palliative Sedation survey

- Burdened by decision for sedation
- Wanted more information prior to starting sedation
- Overall positive experience
- Improved symptom control
- Hastening death worries

Experiences of Family Members of Dying Patients Receiving Palliative Sedation
Olga Tursunov, RN, MSc, Nathan I. Cherny, MBBS, FRACP, FRCP, MD, and Freda DeKeyser Ganz, PhD, RN

Provider unease/distress

- No agreement on definition
- Not many institutions have guidelines
- Worry about euthanasia
- “Doing no harm”

Table 4. Availability and Use of Palliative Sedation Procedural Guidelines.

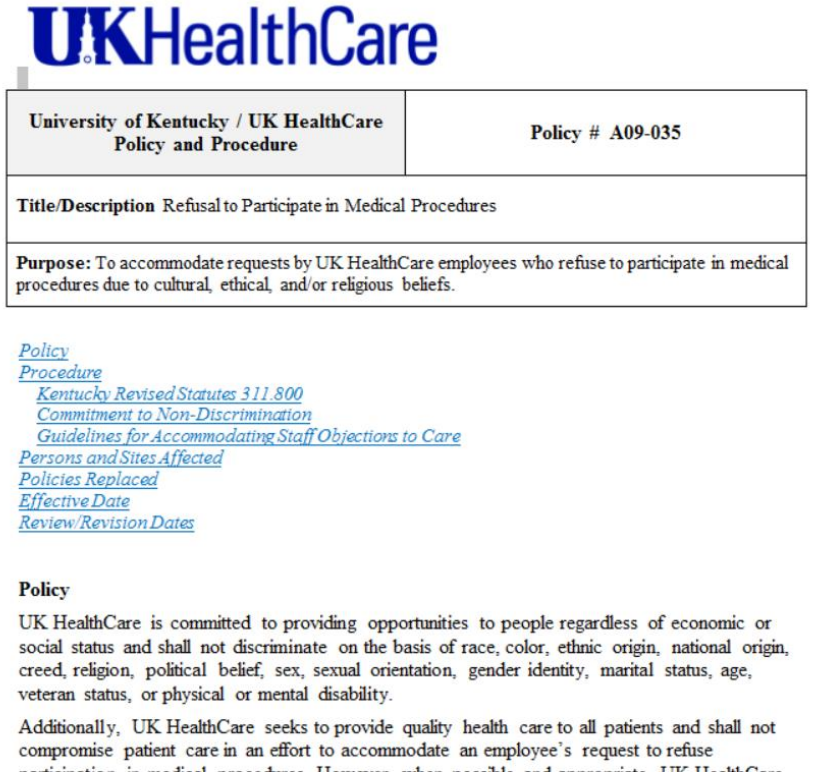
	Frequency	Percentage
Does your institution have procedural guidelines in place for implementing palliative sedation? (N = 679)		
Yes	130	19.1
No	321	47.3
I don’t know	228	33.6
(Skipped)	(152)	(18.3)
(If Yes to the above) How frequently do you, yourself, follow the procedural guidelines? (N = 129)		
Never	1	.8
Rarely	4	3.1
Sometimes	12	9.3
Often	57	44.2
All of the time	55	42.6
(Not asked)	(549)	(66.0)
(Skipped)	(153)	(18.4)

Pediatrician Ambiguity in Understanding Palliative Sedation at the End of Life
Carrie M. Henderson, MD1, Michael FitzGerald, PhD2, K. Sarah Hoehn, MD, MBE3, and Norbert Weidner, MD2

Conscientious Objection

- Refusal to participate in care that violates deeply held beliefs
  - Abortions, Contraception

- At UK employees can petition to not participate in care that violates their cultural, ethical or religious beliefs
- Within reason, accommodations can be made on a case by case basis
- Cannot be cover for discrimination



UKHealthCare

University of Kentucky / UK HealthCare Policy and Procedure	Policy # A09-035
Title/Description Refusal to Participate in Medical Procedures	
Purpose: To accommodate requests by UK HealthCare employees who refuse to participate in medical procedures due to cultural, ethical, and/or religious beliefs.	

Policy
Procedure
Kentucky Revised Statutes 311.800
Commitment to Non-Discrimination
Guidelines for Accommodating Staff Objections to Care
Persons and Sites Affected
Policies Replaced
Effective Date
Review/Revision Dates

Policy

UK HealthCare is committed to providing opportunities to people regardless of economic or social status and shall not discriminate on the basis of race, color, ethnic origin, national origin, creed, religion, political belief, sex, sexual orientation, gender identity, marital status, age, veteran status, or physical or mental disability.

Additionally, UK HealthCare seeks to provide quality health care to all patients and shall not compromise patient care in an effort to accommodate an employee's request to refuse

AMA Opinions

- AMA insists that “physicians’ ethical responsibility [is] to place patients’ welfare above the physician’s own self-interest” (Opinion 1.1.1)
- AMA permits physicians to refuse to treat patients who are seeking care that is “incompatible with the physician’s deeply held personal, religious, or moral beliefs” (Opinion 1.1.2[a])
- should not “unduly burden” patients, does not apply in emergencies or to patients’ end-of-life decisions

Physicians, Not Conscripts — Conscientious Objection in Health Care

Ronit Y. Stahl, Ph.D., and Ezekiel J. Emanuel, M.D., Ph.D.

NEJM 2017

- “To invoke conscientious objection is to reject the fundamental obligation of health care”
- “The health care professional who wants to prioritize personal values over professional duties must choose a less personally fraught occupation”
- “Laws may allow it….but professional medical associations should insist that doing so is unethical”

April 6, 2017
N Engl J Med 2017; 376:1380-1385

Rebuttal

- “Medical profession used to view eugenics as acceptable and homosexuality as a disease”
- “Voices of conscientious objectors eventually influenced the field”

Letters

Lester Liao, M.D., M.T.S., University of Alberta, Edmonton, AB, Canada
Ewan Goligher, M.D., Ph.D., University of Toronto, Toronto, ON, Canada

CORRESPONDENCE

Conscientious Objection in Health Care

TO THE EDITOR

Stahl and Emanuel (April 6 issue)[1] rightly differentiate between conscripts and physicians. Nonetheless, they state, “the profession . . . uses reflective equilibrium to self-correct. This dynamic process establishes professional obligations . . . regardless of . . . personal beliefs.”[1] This point fails to recognize that conscientious objectors are engaging in the dynamic process from within the profession to counter problematic professional obligations and to correct mistakes. The medical profession no longer accepts eugenics and no longer views homosexuality as a disease because the voices of conscientious objectors eventually influenced the field. Without permission for individual dissent, the dynamic equilibrium becomes entirely static. Moreover, the authors give no reason to think that the dynamic equilibrium always moves the profession toward something approximating moral truth.