

Not Always Life and Death: Ethics and Palliative Care in Primary Care Pediatrics

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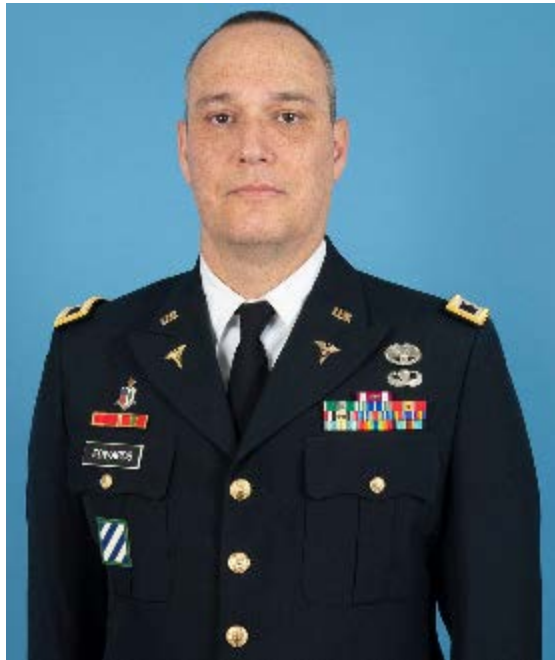
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LCDR Sebastian Lara, MD, MA, FAAP is Assistant Professor of Pediatrics and the Assistant Clerkship Director for Pediatrics at the Uniformed Services University. He graduated from the University of Notre Dame and then received his Doctor of Medicine and Master of Arts degree in Bioethics and Medical Humanities from Northwestern University. He completed his residency in Pediatrics at the National Capital Consortium at Walter Reed National Military Medical Center, and then served an additional year there as Chief Resident. During his three year tour as a general pediatrician at Naval Hospital Guam, he served as Chair of the Healthcare Ethics Committee and also participated as the sole pediatrician aboard the USNS Brunswick component of Pacific Partnership 2018 humanitarian mission. Research interests include medical education, narrative medicine, and global health.

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COL Edwards received his medical degree from the Philadelphia College of Osteopathic Medicine and completed his internship and residency in Pediatrics at Tripler Army Medical Center. COL Edwards was commissioned in 1997 as a 2LT in the Medical Service Corps at the United States Military Academy at West Point. COL Edwards' assignments include Staff Pediatrician at Blanchfield Army Community Hospital, Fort Campbell, Kentucky; Pediatric Hematology/Oncology Fellow at Walter Reed Army Medical Center, Washington, DC; Chief of Pediatric Specialties at Tripler Army Medical Center, Honolulu, Hawaii; Hospice and Palliative Medicine Fellow at University of Washington, Seattle, Washington; Deputy Chief of Pediatrics at Tripler Army Medical Center, Honolulu, Hawaii and Chief of Pediatrics at Tripler Army Medical Center, Honolulu, Hawaii. He is currently assigned as a Pediatric Palliative Medicine Staff Physician at Walter Reed National Military Medical Center. COL Edwards also served as the Chair of the Medical Ethics Committee at Tripler Army Medical Center from 2016 until 2019 and is a certified Healthcare Ethics Consultant through the American Society of Bioethics and Humanities.

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Learning Objectives



At the conclusion of this activity, participants will be able to:

1. Recognize the medical ethics principles that a pediatric provider uses in everyday practice and construct an approach to weigh these principles when making a decision.
2. Discover the role for palliative medicine as it applies to primary care pediatric patients and know DoD palliative medicine and ethics resources.
3. Apply this learned approach to analyze several patient situations.

Why these two topics?



- In our medical training, ethics and palliative medicine are typically associated with end-of-life care
- For those practicing in a primary care setting (fortunately in pediatrics), this is not common
- BUT...these concepts still apply and are still important!

Three patients...



- 5 year old girl due for annual influenza vaccine

- Screams NOOOO!

- Polling Question

- Proceed with shot

- Do not give shot

Image sources: <https://www.cmu.edu/dietrich/news/news-stories/2018/april/gretchen-chapman-vaccination-behavior.html>
<https://www.themonastery.org/blog/anti-vaccine-mom-realizes-mistake>

Second patient...

- 17 year old female, sexually active. Mother requests placement of a long acting reversible contraceptive rod

- Screams NO!
- **Polling Question**
 - Proceed with rod placement
 - Do not place rod



Image source: <https://www.spokesman.com/stories/2012/sep/20/iuds-implants-urged-for-teen-girls-birth-control/>

Third patient...



- 10 year old boy with multiple warts on his hand. Parents request cryotherapy (cryo).

- Screams NOO!
- **Polling Question**
 - Proceed with cryo
 - Do not perform cryo

Image Source: https://www.babycenter.com/0_warts-in-babies_1443878.bc Biophoto Associates / Science Source

What factors make these different?



- Age
- Risks/harms of procedure or intervention
- Benefits to the child
- Agreement of the child

Ethical Principles



- Most of us learn in training one particular approach to medical ethics...four principles

- Autonomy
- Beneficence
- Non-maleficence
- Justice

Beauchamp T L, Childress J F. *Principles of Biomedical Ethics*. 5th ed. Oxford University Press, 2001.

Four Principles



Autonomy

- Patient's right to make decisions for themselves after being informed
- Requirement to have *capacity* to make a given decision
- Informed consent vs assent

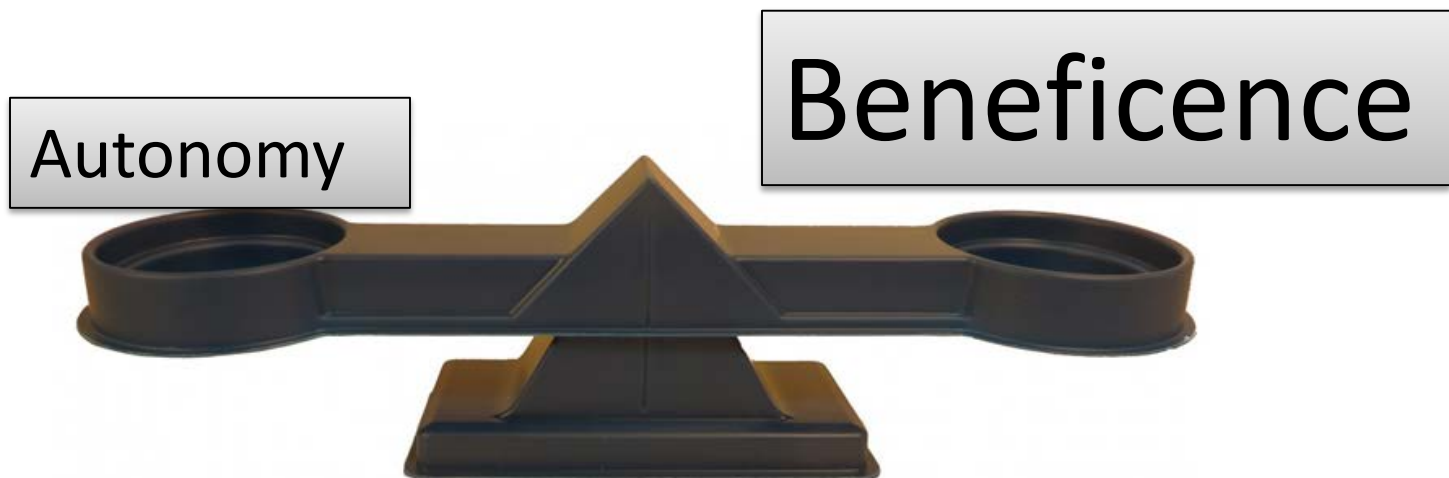
Beneficence

- Obligation to act in the best interests of the patient
- Make decisions that maximize benefits

These principles require a very careful balance, especially in pediatrics...

Unique Features of Pediatrics

Children cannot fully appreciate the risks/benefits or long-term consequences of their decisions, so they have limited autonomy



We Trust Parents

- Parents given wide latitude to exert autonomy regarding decisions for their children
- But there are limits: providers have special role as advocates to ensure acting in their children's best interest. Case: child abuse or neglect



Image: www.preventchildabuse.org

All children deserve
great childhoods
because our children
are our future.

Four Principles



Non-maleficence

- Minimizing harm necessary in order to achieve the beneficial outcomes
- Can be physical or emotional harm to the patient and/or the family. Also financial harm.
- Case: Unproven therapies

Justice

- Obligation to act and make decisions fairly in between competing claims
- Common situation: fair distribution of scarce resources
- Case: Stimulant medications – performance enhancement

Two Additional Principles



Veracity

- Ethical obligation to tell the truth to our patients
- Avoid misrepresentation or deceit.
- Report lapses in care
- Case: New diagnosis of pediatric cancer

Confidentiality

- Ethical obligation to maintain the privacy
- Critical for establishing a relationship of trust with adolescents
- There are limits
- Case: Teen with STI

Approach



- What are the facts?
- Who are the stakeholders?
- Weigh the applicable principles.
 - Respect for autonomy – maturity
 - Beneficence – what’s in the best interest of the patient?
 - Non-maleficence - what are the harms of potential decisions?
 - Justice – are the actions fair?
- Consider alternatives

Apply this approach to the initial cases



- Facts?
 - Stakeholders?
 - Weight of the Principles
 - Autonomy
 - Beneficence
 - Non-maleficence
 - Justice
 - Alternatives?
- 5 year old refusing annual influenza vaccine
 - Recommended vaccine
 - Child, parent, provider

 - Not mature enough to appreciate
 - Prevention of serious illness
 - Temporary pain, minor side effects
 - No issues
 - Defer the vaccine

Apply this approach to the initial cases



- Facts?
 - Stakeholders?
 - Weight of the Principles
 - Autonomy
 - Beneficence
 - Non-maleficence
 - Justice
 - Alternatives?
- 17 year old refusing contraceptive rod requested by mom
 - Indicated. Probe reasoning
 - Child, parent, provider

 - Nearly adulthood
 - Prevention of unwanted pregnancy
 - Temporary pain, minor side effects
 - Aware of other options?
 - Other contraceptive vs. counseling only

Apply this approach to the initial cases



- Facts?
 - Stakeholders?
 - Weight of the Principles
 - Autonomy
 - Beneficence
 - Non-maleficence
 - Justice
 - Alternatives?
- 10 year old refusing cryotherapy
 - Warts benign, treatment not mandatory
 - Child, parent, provider
 - Developing understanding
 - Higher chance of clearing
 - Temporary pain, minor side effects
 - No issues
 - Continue topical treatment vs none

Apply this approach to more complex case...



- 16 year old female with consistent male gender identity for several years
- Parents having difficulty accepting this
- Patient having significant anxiety and dysphoria
- Followed by mental health
- At primary care visit, asks for hormonal treatment to transition. Does not desire surgery.

Issue: Gender-Affirming Hormonal Therapy



- Facts?
 - At puberty, strongly consistent
- Stakeholders?
 - Child, parents, provider, Tricare, state law, hospital policy
- Weight of the Principles
 - Autonomy
 - Near adulthood, parents hesitant
 - Beneficence
 - Evidence for mental health benefits
 - Non-maleficence
 - Very limited data on long term effects
 - Justice
 - Significant barriers to equal care
- Alternatives?
 - Watch & wait, refer, social transition

(Kimberly L. et al, 2018)

Stakeholders beyond the patient



- Law: e.g. from the news: South Dakota recent legislation Bill 1057 (defeated Feb 2020) proposed to make it a misdemeanor to provide gender-affirming medical therapies to patient under age 16¹
 - Insurance: Will Tricare pay for this?
 - Provider: Controversial, what if against conscience?
 - Parents: What if one parent agrees, one does not?
- IMPORTANT to know local laws and policies

¹<https://www.thehastingscenter.org/medical-intervention-for-transgender-children/>

Pivot to Palliative Medicine Discussion



- In clinical situations that involve a conflict between stakeholders, communication is often key
- We can apply some communication strategies that have been developed in the field of palliative medicine to help...

Palliative Medicine



- The relieving or soothing of symptoms of a disease or disorder while maintaining the highest possible quality of life for patients.
- Patient-centered care for people of any age, at any stage in illness, whether that illness is curable, chronic or life-threatening.

Palliative Medicine Background



- To become board certified in Hospice and Palliative Medicine, a physician must complete a 12-month fellowship.
 - Practice Pathway to certification was stopped in 2012
 - Joint Centralized Credentialing and Quality Assurance System (JCCQAS) requires fellowship completion or board certification for granting of Palliative privileges.
- Additional training routes are available for advance practice nurses, social workers, chaplains and other disciplines

When to think of Palliative Medicine?



- Patients in whose symptoms are chronic and/or have significant effect on quality of life.
- Patients (or families) with poor prognosis or difficulty understanding/accepting diagnosis.
- Chronic pain syndromes.
- Patients with rare diseases and poor support systems.
- Anytime a patient or family needs an extra layer of support.

Palliative Medicine Concepts



■ Symptom management

- Pain
- Nausea
- Stress

■ Communication skills/Setting goals

- Difficult conversations
- Advance Care Planning
- Conflicts

14 year old female with leg pain



- Competitive dancer, fell on stage a few weeks ago onto her knee. Complains of increasing knee pain
- Benign exam, normal plain films...conservative care
- Worsening pain, can barely walk, school absences
- Hyperalgesia, pain out of proportion to exam

Complex Regional Pain Syndrome



- Multi-modal approach to pain
- More medication is not necessarily the best answer
- Concept of “total pain”
- Non-pharmacological interventions
 - Acupuncture
 - Cognitive behavioral therapy
 - Guided visualization/mindfulness
- Focus on goals of patient and adapt interventions with goal in mind

6 year old with genetic syndrome



- Developmental delay
- During common illnesses, often stops drink and becomes dehydrated requiring admission
- Care team asks: can we place a g-tube?
- Parents refuse more aggressive interventions.
- **Polling Question**
 - Proceed with g-tube placement
 - Do not place g-tube
 - Don't know/Unsure

6 year old male with Angelman Syndrome



- Parents concerned that moving to aggressive treatments means that they failed as caregivers
- Parents conflicted because admissions required multiple IV attempts, arm boards that restricted movement, so did affect quality of life for their son
- By eliciting specific concerns, was then able to address each to build rapport and consensus
- Shared decision-making model for patient-centered care

Coronavirus (COVID-19)



- Many ethical issues to consider
 - ❑ Justice – ventilator and bed supply
 - ❑ Beneficence – triage
 - ❑ Autonomy – mandatory quarantine
 - ❑ Non-maleficence – experimental therapies / vaccine accelerated approval

Who can you ask for help?



■ Ethics consultations

- Ethics Committee at your local MTF
 - Advisory role – ultimate decision resides with the provider
- DoD Medical Ethics Center (DMEC)
 - Developing DoD wide ethics resources/curriculum
 - Centralized expert panel for Ethics Committee's to access

■ Palliative Medicine Experts

- Located at Walter Reed-Bethesda, Madigan Army Medical Center, Brooke Army Medical Center, and civilian tertiary care pediatric centers.

Key Takeaways



- You make ethical decisions every day when taking care of pediatric patients—take note
- Best interest of the child usually carries the most weight— respect emerging assent
- Use palliative care concepts of pain control and communication of goals for pts with chronic issues
- You have resources in your MTF Ethics Committee and your Pediatric Subspecialists for tough cases

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 - b. Complete the Evaluation
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