Case #1

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- 5 days old, female patient, transferred from another state with bilious emesis.

Day of Life One

With this image, what would be your next step?

1. Upper GI
2. Rectal biopsy
3. Contrast enema
4. Abdominal ultrasound
5. I don’t know

Normal Upper GI = No Malrotation

H: 0 %
F: 30 %

Day of Life 2

R

AJT

Day of life 5

Upon arrival at the hospital

Day of life 7: Underwent suction rectal biopsy

Day of life 8

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Day of life 9

Underwent laparoscopic leveling biopsies and ileostomy on day of life 10

15 days post-op

- Did not tolerate feeds
- No stoma output
- No successful irrigations from rectum nor from ileostomy

What would you do now?

1. Exploratory laparotomy and small bowel biopsies
2. Exploratory laparotomy and stoma revision
3. Exploratory laparotomy and G tube insertion
4. I don't know

Diagnosed with Total Intestinal Aganglionosis

- Stoma creation at 15 cm from ligament of Treitz
- Later had a G tube insertion
- Patient is a Jehovah's Witness and has chronic kidney disease (single hypoplastic right kidney)

Challenges

- Chronic need for total parenteral nutrition
- Jehovah's witness: no blood transfusions
- Not a candidate for kidney transplant only due to incapacity to absorb oral immunosuppression
- Long-term possible options: multi-visceral transplant (kidney and intestine)

Palliative Care

- Not just end of life or hospice
- Extra layer of support for patients and families with life limiting or life altering diagnosis
- Advanced symptom management
- Help to prepare for the future
- Ensure goal concordant care

Primary Palliative Care

- Skills that all surgeons should possess:
  - eliciting goals of care
  - assessing symptom burden
  - ensuring good transitions of care

Specialty palliative care:
  - multidisciplinary care
  - advanced symptom management
  - information about hospice options

Surgical Palliative Care

- Balfour Mount, MD who coined the term palliative care was a surgeon
- Surgeons frequently are involved in high intensity, high risk decisions with families

1. Respect the dignity and autonomy of patients, patients' surrogates, and caregivers.
2. Honor the right of the competent patient or surrogate to choose among treatments, including those that may or may not prolong life.
3. Communicate effectively and empathically with patients, their families, and caregivers.
4. Identify the primary goals of care from the patient's perspective, and address how the surgeon's care can achieve the patient's objectives.
5. Strive to alleviate pain and other burdensome physical and nonphysical symptoms.
6. Recognize, assess, discuss, and offer access to services for psychological, social, and spiritual issues.
7. Provide access to therapeutic support, encompassing the spectrum from life-prolonging treatments through hospice care, when they can realistically be expected to improve the quality of life as perceived by the patient.
8. Recognize the physician's responsibility to discourage treatments that are unlikely to achieve the patient's goals, and encourage patients and families to consider hospice care when the prognosis for survival is likely to be less than a half-year.
9. Arrange for continuity of care by the patient's primary and/or specialist physician, alleviating the sense of abandonment patients may feel when "curative" therapies are no longer useful.
10. Maintain a collegial and supportive attitude toward others entrusted with care of the patient.

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Pediatric Palliative Care & Surgery

- Developmental differences across a child's life span
- Majority of referral to palliative care in kids are in complex chronic illness
  - Palliative care can be provided concurrently with disease directed therapies. Help to navigate multiple specialists centralize communication and prioritize goals

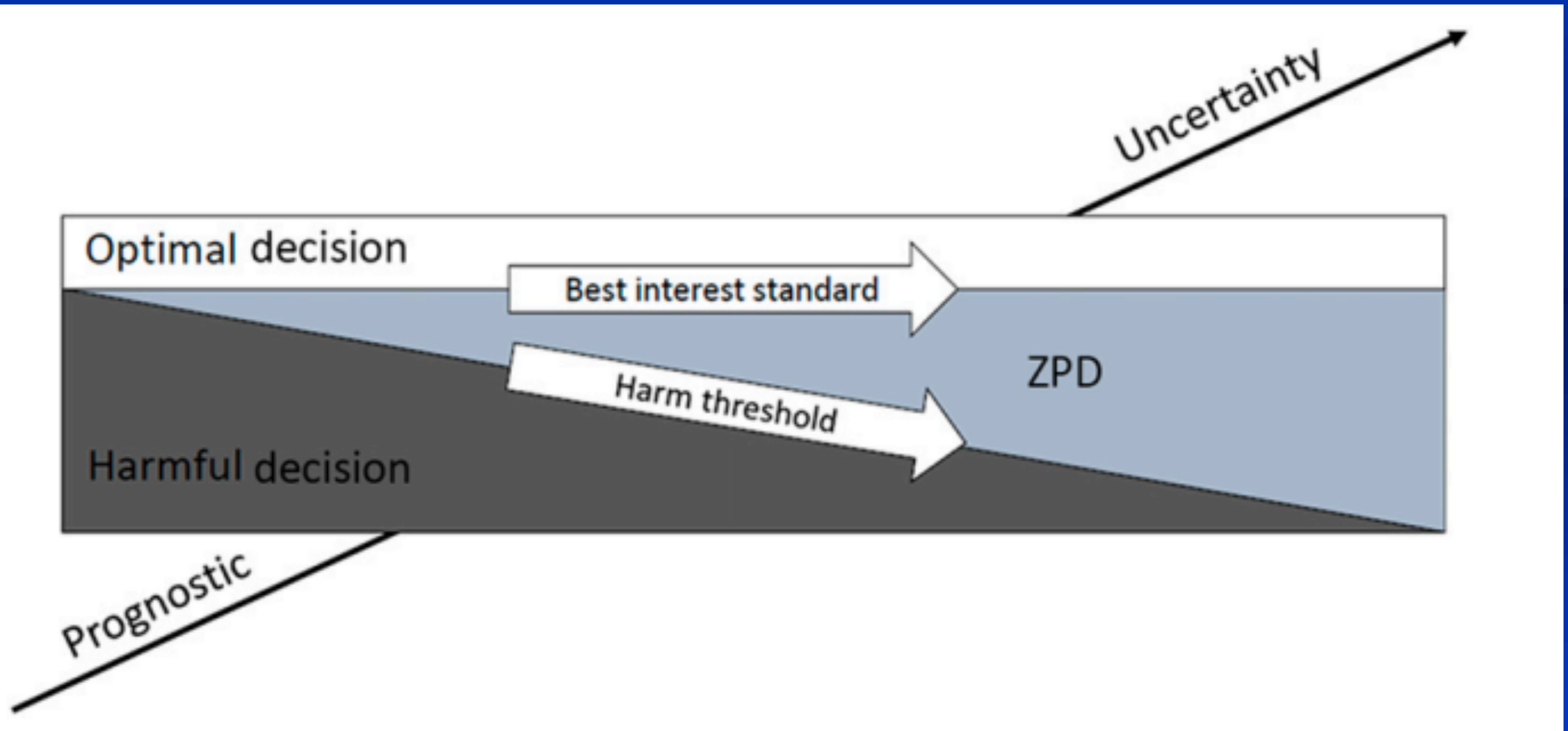
Ott KC, Vente TM, Lautz TB, Waldman ED. Pediatric palliative care and surgery. Ann Palliat Med. 2022 Feb;11(2):918-926. doi: 10.21037/apm-20-2370. Epub 2021 Jul 6. PMID: 34263644.

Primary Palliative Skill: Prognostication

- First step in goals of care conversation is to ground the discussion in prognosis
  - Time and quality

- Short gut
  - Central line complications
  - TPN dependence
  - Medication absorption challenges
- Chronic kidney disease
  - Multi - visceral transplant

What is the right decision? Zone of parental discretion



Janine Penfield Winters (2018) When Parents Refuse: Resolving Entrenched Disagreements Between Parents and Clinicians in Situations of Uncertainty and Complexity, The American Journal of Bioethics, 18:8, 20-31, DOI: 10.1080/15265161.2018.1485758
Jeanne A. Krick, Jacob S. Hogue, Tyler R. Reese, Matthew A. Studer; Uncertainty: An Uncomfortable Companion to Decision-making for Infants. *Pediatrics* August 2020; 146 (Supplement_1): S13–S17. 10.1542/peds.2020-0818E

Thank you.

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