Master Clinician Series

When Aligning is Hard: Treatment Planning for Children Living with a Serious Illness

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Objectives

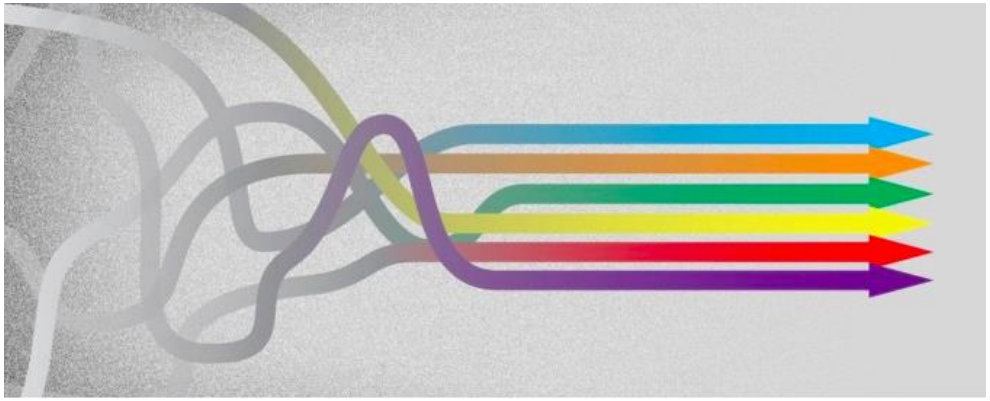
- Recognize the importance of alignment between families and clinicians in pediatric palliative care, and when it can be difficult
- Describe a 5-step approach to use in situations where alignment is challenging
- Apply the approach to 3 clinical cases

Outline

- Discuss alignment
- Review a 5-step approach to support alignment
- Apply these steps to three clinical cases

What is alignment?

- When the child/family/clinicians:
  - feels heard and supported
  - openly share hopes/fears/worries
  - have trust and mutual respect
  - know unmet needs are seen and being addressed



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When aligning is easier…

- Plan of care is mutually agreed upon, with sufficient mutual understanding

OR

- Patient/families/teams can easily recognize and address unmet needs, including:
  - Physical, emotional, social, spiritual needs
  - Gaps in medical understanding

When is aligning challenging?

- Multiple perspectives within a family or primary teams
- Barriers to empathic communication
  - Implicit/Explicit bias
  - Unfamiliar expressions of cultural/religious beliefs
- Family/Clinician disagreement over most beneficial plan of care
  - Refusal of treatment
  - Request for treatment felt to be non-beneficial
  - Request for treatment not supported by current medical science
- One party is potentially causing a child's illness
  - Medical child abuse or non-accidental trauma

So what do we do about it?

- What we already do, but more so
- AFGO

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Case 1: Jose

- Jose is a 20-year-old man with Duchenne's Muscular Dystrophy, admitted for aspiration pneumonia. Jose is a beloved member of his family and school/church community. His parents are Spanish-speaking and Jose is bilingual in English/Spanish.

- He was admitted to the hospital from pulmonary clinic, with dyspnea, hypoxia. 10-pound weight loss over last 4 months is also noted. Pulmonary team recommends g-tube placement, as they have for the last 12 months. His parents want to follow medical plan. Yet Jose has repeatedly elected not to pursue g-tube placement.

- Palliative care consulted by primary team to "help convince" Jose that he "needs a g-tube."

5 step approach to support alignment

- ➔1. Take your own pulse first
- ➔2. Identify strengths and unmet needs
- ➔3. Engage others
- ➔4. Develop a plan
- ➔5. Hold the space

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1. Take your own pulse first

- ➔ Explanation: Attitude of humble inquiry
  - Remember our agenda is to be curious and present
  - Seek to understand
  - Recognize our own triggers and biases

Macauley R. Journal of Palliative Medicine 2011;
Macauley, R. Personal communication
Rosenberg A, Bona K, Coker T et al. JPSM April 2019

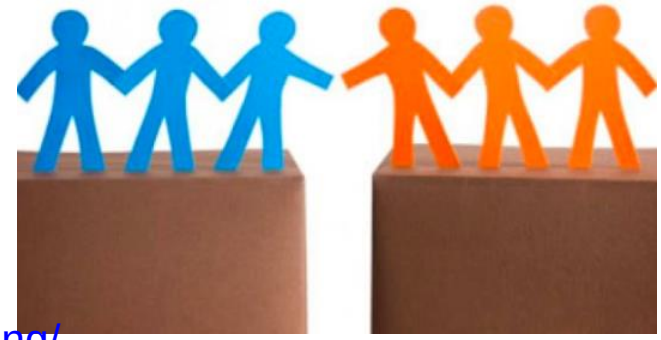
1. Take your own pulse first

➔ "Jose" case example:

- Held the story of "non-adherence" lightly
- Recognized our potential bias about feeding tubes in late stage disease

2. Identify strengths and unmet needs

- Explanation:
- Acknowledge emotions/allow space for them
- Assess understanding of the situation, hopes/fears/values, sources of strength
- Helpful skills:
  - NURSE skills to respond to emotions
  - best case/worst case/ most likely scenarios



Maron J, Jones E, Wolfe J. JPSM 2018;
https://www.vitaltalk.org/guides/responding-to-emotion-respecting/
Kruser J, Nabozny M, Steffens N et al. J Amer Geriatric Soc, 2011

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2. Identify strengths and unmet needs *continued*

- Listen for what they need, not just what they think/say
  - Assume everyone has the need to be heard and respected
  - What other needs are there?
    - Parent: to be a “good parent;” hold hope and worry at the same time; basic family needs
    - Clinician: need to fix, to receive thanks, need to acknowledge feelings of guilt, grief

Feudtner C. Pediatric Clinics of North America October 2007

2. Identify strengths and unmet needs

- ➔ "Jose" case example:
  - Jose
    - Good understanding of DMD, g-tube
    - Values sharing family meals and food
    - Need for self-determination
  - Parents
    - "Good parent" beliefs about feeding
    - Recognition: "Its not what I would do for myself, but its his body"
    - Reflect the value of supporting Jose's autonomy
  - Primary team
    - Grief/guilt over disease progression

3. Engage others

- Explanation: Who can help recognize and meet these needs?

- Spiritual care
- Expressive therapists
- Child life
- Ethics committee
- Department of children's services
- Courts

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3. Engage others

➔ “Jose” case example:

- Child life therapist: supports Jose’s autonomy
- Chaplain: supports mother with prayers, scripture
- Staff support coordinator: meets with care team

4. Develop a plan

- Explanation:
- Original medical plan may need to shift
- Move away from black and white thinking
- Recognize that with time, the clinical situation and family/providers perspectives may change

Maron J, Jones E, Wolfe J. JPSM 2018

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4. Develop a plan

➔ "Jose" case example:

- Helped reflect Jose's awareness and perspective on his own quality of life and values
- Discussed with team who agreed that benefit of g-tube was marginal
- Supported everyone's anticipatory grief
- Outcome: Plan to have OT guidance on safest ways to eat, referral to hospice

5. Hold the space

- Explanation:
- Continue to accompany the family and team
- Encourage compassion:
  - Remind yourself and your colleagues that this family is experiencing trauma
- Minimize harm to the team and family
  - Communicate, communicate, communicate

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5. Hold the space

➔ "Jose" case example

- Created opportunities for family and team to share sadness
- Team stopped bringing g-tube up every visit
- Warm hand-off to hospice
  - Shared understanding of concurrent goal

Case 2: Justin

- “Justin” is a 4 week old baby born at 35 weeks with complex congenital heart disease, IUGR, pulmonary hypertension, congenital diaphragmatic hernia. Intubated in NICU since birth, on inhaled nitric oxide; not a candidate for cardiac surgery due to lung hypoplasia.

- Palliative care consulted to help with goals of care. NICU team shares that the parents “don’t get it” and that they find the parents “difficult to talk to” and “hard on nursing staff”

Steps

- 1. Take your own pulse first
  - Approached family with open perspective
  - Aware of bias about “futile” care for child, and considered “total suffering” of family
- 2. Identify strengths and unmet needs
  - Parents: good understanding of prognosis, holding hope and worry, primary goal was comfort
  - Primary team worry was causing suffering
  - Mother was aware of nurses’ disapproval of decisions; led to conflict
- 3. Engage others
  - NICU social worker, child life, spiritual care: all provided on going support

Steps, Continued

- 4. Develop a plan
  - Continued life sustaining interventions without escalation and had DNR order written
  - All aligned on minimizing pain, discomfort
  - Created opportunities to celebrate Justin's life
    - Siblings artwork
    - Took baby outside to interfaith center
- 5. Hold the space
  - Shared parents' perspective with nursing
  - Continued checking in with family, active management in keeping Justin comfortable, support siblings

Palliative Care Team Self-Care

- ➔ Bring a friend!
- ➔ Create a safe, non-judgmental space to share your feelings and doubts, without trying to fix
- ➔ Consider (self)compassion practices

Pier TJ. Integrating Mindfulness into Palliative Care: Caring for ourselves, NHPCO 2017

How the past informs the future

- Carrying the hard ones forward – within ourselves, our teams, and our collegial relationships
- Notice if the impulse arises to think “this family is just like that (challenging) one”
- Consider how lessons learned for our patients/families can live alongside our openness to encounter each patient/family anew

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Take Home Points

- Remember the 5 steps to support alignment:
  - 1. Take your own pulse first
  - 2. Identify strengths and unmet needs
  - 3. Engage others
  - 4. Develop a plan
  - 5. Hold the space

Thank you!

Don’t forget to continue the conversation on the CAPC ‘Master Clinician Series’ Forum

https://central.capc.org/eco_dialog_view.php?id=14

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