Pediatric health care provider perspectives on adolescent and young adult advance care planning in bone marrow transplant

"Informed decision-making is a valuable notion but a faulty tool"

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Introduction

- Advance care planning for adolescent patients is receiving increased attention
- Advance care planning:
  - Gives adolescents a voice
  - Helps surrogates “break the ice”
  - Provides an extra layer of support to providers
- Perspectives of pediatrics providers are relatively unexplored

Methods

- FACE-BMT study
  - ACP intervention
  - Adolescent and young adult patients (ages 14-26) undergoing BMT at the University of Minnesota
- Three focus groups (pediatric ICU and BMT MDs)
- Key questions
  - Describe your experience with advance care planning for adolescent and young adults
  - Discuss your thoughts about the role of advance care planning on informed decision-making in the pediatric ICU
  - Impact of end-of-life decision-making on moral distress

Results

- 15 physicians (11 PICU, 4 BMT)
- Main themes
  - Temporality/role responsibility
  - Limitations of patient/surrogate knowledge and understanding
    - **Lack of embodied knowing and witnessing**
    - **Clinical cascades and the "new normal"**
    - Adolescent capacity
    - Epistemological frames

Theme 1: Temporality

- Should be early in disease course and ongoing
- Foundational

"By the time they're with us in the ICU, the conversations have a really different tenor, and if you don't have the foundational conversations started, they're a much more difficult conversation to have. We all agree that we have a part in having these conversations but they're exceedingly difficult if someone else hasn't started them already."

Theme 2: Limitations of knowledge and understanding

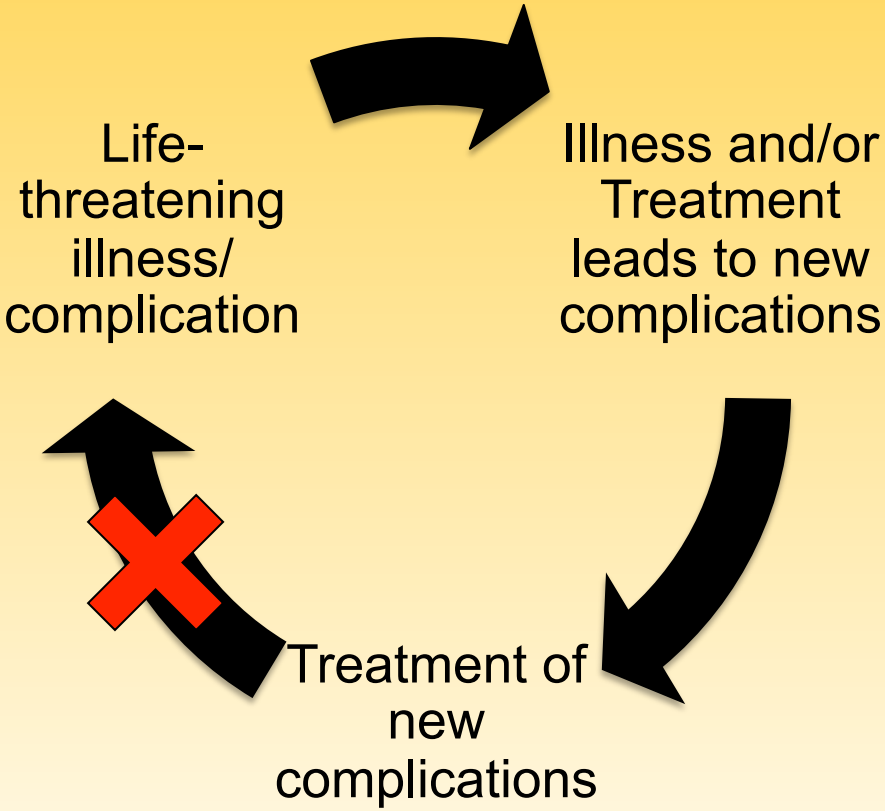
"I think it (ACP) has done really good things but I think that the way that we approach it is a valuable notion but the limitations of it make it a really faulty tool."

Embodied knowing

- Patients often lack “understanding”
- Felt bodily experience as well as knowing the chronic consequences of decisions

“I think the majority of people can’t imagine what this situation is going to be like because they’ve never experienced it. They understand what death is, but when you talk about the nuances of being on life support, I don’t know they really can fully understand that.”

Clinical cascades and the "new normal"



Cascades

… often the longer our patients are sick, the more complications they accrue of their treatment people's conception of what is reasonable and tolerable shifts because the patient and their family's 'normal' has shifted so significantly. Then things that would've seemed completely intolerable, has become not only tolerable, but acceptable. It just continues to perpetuate.

Additional limitations

- Adolescent autonomy and capacity
- Epistemological frames

Conclusions

- Pediatric providers have limited experience with/ knowledge about ACP
- Providers support ACP as an important process for foundational conversations
- Limitations of ACP decisions in acute situations related to conern over “understanding”
- Impact of clinical cascades

Thank you!

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