Integrating Pediatric Palliative Care: Strategies for Improving Communication

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Key steps to advance communication skills in palliative care

- Be willing to talk about difficult topics
- Use communication as an opportunity to build a relationship
- Promote goal-oriented decision-making throughout care
In pediatric oncology, tough conversations occur throughout care

- At diagnosis
- When complications occur
- At relapse
- During advance care planning
- Even in survivorship
Communication is one of our most important interventions

- Allows for the development of shared knowledge
- Relieves distress and uncertainty
- Builds a therapeutic relationship
- Creates an opportunity for thoughtful decision-making based on the personal values of parents and children
Shared knowledge

• Clinicians often think of delivering information as the core role of communication
• Yet even here we are not always successful
Shared knowledge: Prognosis communication

- 61% of parents of children with cancer hold overly optimistic beliefs about prognosis


- Parents of children who died of cancer recognized that the child had no realistic chance of cure 3.4 months after physicians did

- But those who understood this earlier had earlier DNR orders and used less cancer-directed therapy at the end of life

Clinicians need to be prepared to have difficult discussions

• Yet many clinicians worry that bad news has negative consequences for patients and families
  – Distress
  – Loss of hope
• As a result, clinicians sometimes avoid these difficult conversations, wait for patients/parents to ask, speak in euphemisms, or offer overly optimistic information
In fact, honest communication of bad news can be helpful

- Prognosis communication is one example
- Parents of children with cancer consider communication about prognosis to be important and helpful to decision-making, even if they also find it upsetting
- Parents who feel they have too little information about prognosis are those who are most likely to feel upset

Honest communication of bad news can be helpful

- Parents who have received more extensive prognostic information are those who also report feeling most hopeful
  - Even when the child’s prognosis is poor
- Prognostic disclosure is also associated with greater peace of mind and trust in the physician


Why would communication of bad news increase hope?

• Some possibilities:
  – Honest communication relieves uncertainty, which is itself distressing
    • Parents and children are worried about these issues whether or not we address them
  – Communication about difficult subjects affirms that the clinician will be with the parent through tough times
  – Parents who know what is ahead feel more prepared to be there for their children
Ultimately, promoting false hope is not a goal of medicine

- Being with patients and families through hard times is
- Honest, caring communication of bad news is one of the ways we can be there for our patients and families
Developing relationships

• Begins at diagnosis and continues throughout care
• Children and families need to know that their caregiver:
  – Cares about them
  – Can be trusted
  – Respects and listens to them
  – Will continue to be there as the illness evolves
Developing relationships

- No prescribed path
- Yet clinicians can foster a relationship by engaging the child and family in teaching the clinician who they are
Developing relationships

• Most important clinician role is listening
  – Especially with children, who may present occasional openings to important conversations
  – By listening, clinicians teach children and parents that their words have meaning

• Questions have dual roles
  – Allow child and parents to express themselves
  – Give the clinician information that helps in providing the best possible care
Recognizing hopes and fears

- Among the ways we can get to know our patients is honest exploration of what is important to them in their care
- Understanding hopes and fears also sets the stage for formulating goals of care
Eliciting hopes and fears: Guidance from the literature

• As you think about your future, what is most important to you? What are you most worried about?


• What are you hoping for? And what else are you hoping for? And what else?

Eliciting hopes and fears: Additional considerations for parents

• What does it mean to you to be a good parent in this situation?

Eliciting hopes and fears: Additional considerations for adolescents/young adults

• Assess readiness for conversations and engage the family in the decision to talk with the patient

• Focus on topics of importance to young people
  – How I want to be treated
  – Who I want to make decisions for me if I cannot
  – How I want to be remembered

Making decisions

- When a child’s cancer is incurable, we often focus on goals of care as a foundation of decisions.
- But the goals of the child and family are relevant throughout illness.
- Using goal-oriented decision-making throughout care can help with the transition to palliation when the time comes.
Making decisions

- At diagnosis, the primary goal is usually cure
- But even during cure-focused care, parents usually consider palliation a priority


- Similarly, when standard therapy has failed, parents typically want to continue to incorporate both cancer-directed and symptom-directed therapy into care plans

Making decisions

• Making goals a part of decision-making from the time of diagnosis can help us to learn what matters to the parent and child

• Care can be framed in the context of these goals

• Ideally, the clinician makes recommendations about care, rather than relying on the parent to make decisions on their own

• But clinicians must be careful to make sure parent perspectives are heard and understood while making recommendations
Making decisions

- Clinicians often reach a decision about the preferred direction of care, and then present it to parents.
- Parents, however, often wish for a more active role.


- Similarly, parents often seek options beyond those offered by the oncologist.

The good parent model

- Parent beliefs about what it means to be a good parent of a seriously ill child influence their decision-making
  - Parents prioritize attributes such as ensuring the child feels loved, guarding the child’s health, serving as an advocate for the child, and promoting spiritual well-being
  - Understanding good parent beliefs can help guide exploration of values and recommendations about care

Heuristics for parental decision-making

- Parents also employ heuristics (rules of thumb) to encapsulate and express their values and to use as a decision-making compass
  - For example, “I want my child to have quality of life;” “I want the best for my child;” “Everything happens for a reason.”
- Clinicians can listen carefully for these statements, explore them, and partner with parents in supporting these goals.

Starting conversations early

• These conversations are appropriate for all children and their families, regardless of phase of illness
  – Address fears about the future
  – Help clinicians learn what is important to the child and family
  – Allow the clinician, child, and family to know one another as people
Starting conversations early

- Over time, returning to these conversations reassures children that
  - They matter
  - They are known
  - We will do everything possible to uphold their wishes
What can we do to advance communication in palliative care?

• Clinically:
  – Be willing to talk about difficult topics
  – Use communication as an opportunity to build a relationship
  – Promote goal-oriented decision-making throughout care
What can we do to move the field forward?

- Research
  - What are the most effective communication techniques?
- Improvement in patient and family outcomes
  - How can we best help patients and families make decisions for care that are centered on their personal values?
  - How can we most effectively train clinicians (both younger and more established clinicians) in these techniques?
What can we do to move the field forward?

• Resources
  – How do we support the time and effort of clinicians to engage in these encounters?
    • Time intensive, longitudinal conversations
  – How do we support the training programs needed to equip clinicians with the needed skills?