October 2020 Ethics for Lunch - Should Children Be Told They Are Sick or Dying When Their Parents Refuse?

**Panelists:** Cynda Rushton, PhD, RN, FAAN (Moderator)  
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**Background:**  
At the October Ethics for Lunch, the panel discussed the case of K.M., an 11-year-old girl with a history of pre-B cell Acute Lymphoblastic Leukemia (ALL) with multiple relapses. She had previously undergone courses of chemotherapy and immunotherapy, both of which were associated with significant side effects. After her 3rd relapse, she underwent a bone marrow transplant (BMT), requiring a prolonged hospitalization for treatment of acute graft vs host disease. Eight months after the BMT, she was found to have recurrence of her leukemia. Her parents were devastated and requested the team not tell the patient and it was ultimately determined that she was not a candidate for ongoing protocols due to end-organ damage. Her parents then made the difficult decision to focus on palliative care. When the Oncology team encouraged her parents to discuss the relapse and palliative care plan with her in an age-appropriate manner, they refused, stating they worried she would lose her faith in God and God’s plan. They wanted her to enjoy the time she had left with her family and friends without feeling sad or anxious about the end of life.

**Summary:**

The panel examined the clinical and ethical issues that can arise when medical information is withheld from children at the request of their parent(s)/guardian(s). They explored the responsibilities of the medical team to pediatric patients and to their parent(s)/guardian(s), particularly when conflicts arise. Throughout the discussion, how a family’s culture and faith can affect the decision-making about how and when to disclose information to a child, especially if it is against the wishes of the parent(s)/guardian(s). The session concluded with resources that can be provided to help families through difficult conversations about severe illness and end-of-life.

**Key points:**

* Clinicians caring for youth with life-limiting conditions such as cancer may experience conflicting obligations to advocate for the interests of the young person to be told relevant information about their diagnosis, treatment and possibility of death and the interests of their parents to control what information is disclosed and when.
* While clinicians are committed to advancing the best interest of the young person, parents are ethically and legally responsible for decisions for their children and their treatment until they reach the age of majority. Parents are presumed to have their child’s best interest as primary until proven otherwise.
* Clinicians may experience moral distress when they are in situations where young people directly request information about their condition that parents have requested not be disclosed.
* Clinicians have a moral obligation to be honest with their patients. We also have an obligation to honor the authority and autonomy of patients and their parents.
* Being in conversation with parents and children, where there is this perceived conflicting reality, it is the clinical team’s job to find a way to help navigate in a way that honors all involved. If the parent is trying to protect the child, and the child is afraid to broach the subject with the parents, everyone is going through the hardest thing they’ve ever experienced feeling alone.  However open or closed the communication is between the dying child and their parents, love is what is most important.
* It is in the best interest of the medical team to respect the parent’s wishes whenever possible; at times the medical team may need to set boundaries around how they will answer direct questions from the child. Team members’ goals of not lying to the patient can be an important discussion point with the parents.
* The clinical team’s ethical duty to patients and families is to make sure that biases about how communication should occur does not harm the patient or family.  What the team considers “best practice” for disclosure of information might not be right for every family.  Clinicians also have an obligation to develop competence in terms of having these difficult conversations with children and families.  It is incumbent upon caregivers to be committed to having the courage to hold space, to breathe some normalcy into these conversations when patients and their parents are grappling with how to talk about death.
* It is critical to engage with parents early on to establish a mutual medical plan of care.  When there are differences between the goals of the team and the parents, they should be approached via collaborative problem-solving early on.
* Age and developmental level should be taken into consideration when sharing information with children and youth.
  + Young people will have questions, hopes, and fears that are consistent with their developmental age, and these should be recognized and responded to.
  + Focusing on things that are important to children, especially younger children, will help them understand their illnesses.
  + Discussing prior experiences regarding illness and dying that parents and children have shared will help parents understand how to share information with their child or young person.
* Adolescents may have varying degrees of comprehension and understanding of their condition, consequences of the treatment, and understanding of death; some possess the capacities that are congruent with adult decision making while others may have immature or delayed capacities. Each patient should be assessed to determine their level of decision-making capacity and understanding.
* Importance of and motivation for communication between the medical team, parents, and the child is paramount when conflicts about disclosure of information arise
* For the most part, parents who don’t want to talk about their child’s impending death with the child for a few reasons, all of them very human, and far from sinister, they are well-intentioned:
  + Wanting to protect the child is probably most common.
  + Parents believe, “This is my burden to carry for my child.”
  + Not knowing how to talk with the child in a developmentally appropriate way
  + Being scared or in (very appropriate) denial themselves.
    - There is a connection between parent’s fear of their child’s death and illness disclosure to children
  + Feeling that hope and open communication about death are mutually exclusive
  + Concerns that communicating about their dying with the child could contribute to their more rapid demise. Parents may be afraid that their child would give up and lose the will to live and that precious moments would be stolen from them and from their family.
* There are many communities in which cultural concerns play an important part in wanting to keep information about death and dying from children. Cultural tendencies can be a huge driver, and an extra layer to navigate, especially with many international families.
* Parents know their children best- when their children need what information- even if they struggle to provide it.
* It is important to help parents work through their fear and give them confidence in sharing appropriate information with their child.
  + Parents have to build trust in the clinical team.
  + Reframe the conversation- “what can we tell your child?” Or “Other kids and families have told me this was helpful to hear… are you comfortable sharing this?”
* It is possible to give honest, developmentally appropriate information in a way that is not scary.
  + For children through early adolescence, explanations should be concrete and not wade into hypotheticals/ unknowns--which is where most fear resides.
  + Focus on symptoms and what is being done for treatment- children should have autonomy to know why they need medical intervention and what is happening.
* It would seem likely that after her 4th relapse, this child would pick up on the behavioral and emotional cues from parents along with feedback from her body and know what is going on.
  + Sometimes helping the parents realize that their child is aware of more than they are talking about helps them overcome fear of disclosure and allows parents to find ways to share what they want for their child.
* The parents have to live with what was and wasn’t said to their child.
* There are times when conflicts between parents and the clinical team escalate. Clinicians sometimes utilize child welfare (i.e., CPS) earlier than is indicated, saying “but if we’re concerned for neglect, we’re mandated reporters.”  In many situations, if a child is admitted to the hospital, the actual immediate threat to patient safety is low and there is time to allow parents to process information, engage with the medical team, and determine a course of intervention that all can agree to.  If CPS is engaged prior to true collaboration with the family, it appears more as if the team is attempting to coerce the parents to bend to the team’s plan.
* It is rare for the State (i.e., child welfare authorities, CPS) to intervene in parental decision-making about their minor child’s care.  The bar is set quite high purposefully, as there is general governmental and societal belief that parents know best what their children need.  Only in cases of severe risk of significant physical harm is this is modified and, even then, only via court involvement.
* Our job is to make sure we have provided every resource, opportunity, and support to help the family make the best decision they can in the absolute worst time in their lives.
* Patients, parents and clinicians need additional support during these challenging times. Resources such as ethical consultation, moral resilience rounds or other supportive resources can provide clinicians with spaces to discuss their concerns and examine the various pathways to address them.