Pediatric Goals of Care:
Transitioning Into a New Pediatric
Advance Care Planning Policy in Calgary
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DNR Orders:
The Demise of a Dinosaur?

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Pediatric Goals of Care

Objectives:
At the end of the session, the participants will:

1. Be familiar with current literature regarding advance care planning in pediatrics
2. Understand the clinical and ethical obligations to engage patients and families in conversations regarding goals of care
3. Have an ethics framework for conceptualizing pediatric advance care planning
Presentation outline

1. Advance Care Planning and DNR Orders
2. Goals of Care Designation Policy
3. Key Differences Between Adult and Pediatric Policies
4. Ethical Dilemmas in Pediatrics

Advance Care Planning

Definition:

“Advance care planning” is talking with your child’s doctor about short and long-term care goals when your child has a life-threatening illness. It starts with an open discussion about what to expect with the illness. It can include talking about treatment choices and palliative care (care of children who have a life-threatening illness). It can also include writing more formal advance directives.

Advance care planning allows for better communication between a child’s health care team and family. The family can be clear about what kind of care they want for their child. These discussions also help provide family members with information to fully understand the illness and think about the choices they may face in the future.

Advance Care Planning

**Procedural**
- Discussions about short-term and long-term health care goals and treatments
- An extension of usual discussions about the treatment plan

Canadian Pediatric Society. Advance care planning for paediatric patients. Paediatr Child Health 2008;13(9):791-796

**Substantive**
- May include the writing of plans or orders
- Enables parents to “avoid continuously re-explaining their wishes and preferences to the many health care professionals they encounter”

Advance Care Planning

Longitudinal

- Decision-making process occurs and changes over time.


- Multiple discussions about options are often required.

Canadian Pediatric Society. Advance care planning for pediatric patients. Paediatr Child Health 2006;13(9):791-796

Relational

"What families need help with in many end-of-life situations is not a buffing up of their decisional capacities, but compassionate attention to how the events unfolding before them can be made meaningful or bearable. This is ethics, not on the decisional edge of big choices, but in the full human sense of how people get around their world and orient themselves in life-changing situations."


- Moral distress among health care workers is high
- End-of-life decisionmaking presents some of the most ethically difficult work
- Potential for differing values between parents and health care workers
- Survey: "Children were being saved who should not be saved" vs "Children were given up on too soon"

Current Use of DNR orders

- Procedural?
- Substantive?
- Longitudinal?
- Relational?

Procedural?
- Often seen as an administrative necessity
  - "task" at admission
Current Use of DNR orders

**Substantive?**
- Focus on CPR
- Variable inclusion of other resuscitative or life-sustaining measures
- Often presented as a binary decision
- Defined differently across sites and sectors

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**Longitudinal?**
- Largely limited to ICU settings and very near the end of life
- One study:
  - 83% of pediatric deaths in ICU setting
  - 78% were intubated prior to death
  - 79% had DNR order written during final hospital admission
  - Median time from DNR order to death < 1 day


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**Relational?**
- Often seen as a task rather than a dialogue
- No established decision-making process
- No consistent documentation of decisions
- Access to documentation unreliable
- Often seen as exclusive to physician role
Goals of Care Designation Policy: Overview

• Practice change
• Supported by policy, and legislation
• Standard of care
• Provide guidance regarding ideal care decisions

Goals of Care Designation Policy: The Rationale for Change

• Create single policy and processes in all sectors
• Replace Levels of Care and DNR orders with Goals of Care Designations
• Support families to express wishes in the context of medically appropriate treatments and locations of care

Goals of Care Designation Policy: Key Elements

Elements of Conversation
• Diagnosis and prognosis
• Family’s values, hopes, and expected outcomes
• Life support interventions and life-sustaining measures and anticipated degree of benefit and/or burden
• Comfort measures
• Decision support resources such as social work, spiritual care, and palliative care
• Goals of Care Designation
Goals of Care Designation Policy: Key Elements

**Goals of Care** are health care goals established through Advance Care Planning conversations between health care providers and patients/families.

**Goals of Care Designations** are letter/number codes that provide direction regarding specific health interventions, transfer decisions, locations of care and limitations on interventions for a patient as established and recorded by the Most Responsible Health Care Provider.

**Medical Care and Interventions, focused on Comfort/Symptom Relief**

Goals of Care: directed at symptom control rather than at cure or control of a child's underlying condition that is expected to result in death. Interventions are for symptom relief. These children choose not to receive care in an ICU or would not be expected to benefit from ICU care (except in cases where ICU is determined to be the best location for delivery of symptom-based care).

**Medical Care and Interventions, excluding Resuscitation**

Goals of Care: directed at cure or control of a child's condition, however, care and comfort are the primary considerations. These children choose not to receive care in an ICU or would not be expected to benefit from ICU care (except in cases where ICU is determined to be the best location for delivery of symptom-based care).

**Medical Care and Interventions, including Resuscitation and ICU**

Goals of Care: directed at cure or control of a patient's condition. The child would desire ICU care and would be expected to benefit from ICU if their condition warrants.

**Medical Care and Interventions, focused on Comfort/Symptom Relief**

Goals of Care: directed at symptom control rather than at cure or control of a child's underlying condition that is expected to result in death. Interventions are for symptom relief. These children choose not to receive care in an ICU or would not be expected to benefit from ICU care (except in cases where ICU is determined to be the best location for delivery of symptom-based care).

**Pocket Card**

**Advance Care Planning**

1. Diagnosis and prognosis of cancer or cancer treatment
2. Value of pill your understanding of treatment and its goals
3. Unwillingness to continue or withdraw treatment
4. Life-sustaining measures, if needed (cardiac pacing, internal ventilator device)
5. Consent to resuscitation and resuscitation
6. Goals of Care Designation

Calgary Health Region
Golden Triangle - Clinical Version
Goals of Care Designation Policy: Key Elements

Goals of Care Designation Order

- Medical order
- Paper or electronic
- Becomes a guide for interventions, aligned with agreed upon goals of care
- A copy of the order accompanies the patient upon transfer
- Validated or changed by the receiving physician

Goals of Care Designation Policy: Processes

1. Initiate and follow-up on Advance Care Planning conversations related to Goals of Care
2. Document outcomes of Goals of Care conversations on the Advanced Care Planning Tracking Record
3. After clarifying Goals of Care, determine a Goals of Care Designation
4. Goals of Care Designations are documented as Goals of Care Designation Orders

Key Differences from Adult Policy

- Applies only when clinically relevant
- Respects child/family dynamic
- Provision for Mature Minor
- Location of care options unique to pediatrics
R3 - Medical Care including ICU admission if required, without intubation or chest compressions

The individual is expected to benefit from or be accepting of physiological support in the ICU.

Intubation and chest compression would not be instituted as they would not change the outcome.

If individuals with an R3 designation are already located in an acute care hospital, they are candidates for a Code Blue.

Individuals outside of a hospital would be transferred to an Acute Care Hospital for investigation and treatment that is not available at their current location.
I always knew that one day I would take this road but Yesterday I did not know Today Would be the day.

Nagarjuna

Other Key Differences

Ethical Dilemmas in Pediatrics

Autonomy
- Family Decisions
- Mature Minors
- Potential for Conflicts
- Third Party Respect for Autonomy / Impediments to Ethical Action
- Cultural Considerations & Sensitivities
- Children Without Families
- Children Who are Parents


Cultural Considerations & Sensitivities
- Canadian Paediatric Society, Advance Care Planning for Paediatric Patients/ToolTip,-Sentimental, 2008-02

Autonomy
- Mature Minors
  - legally not an adult
  - cognitive ability to consider treatment choices and alternatives
  - ability to comprehend risks and benefits, and weigh consequences, benefits and burdens
  - effective, ‘age-appropriate’ conversations about goals of care

Canadian Paediatric Society, Advance Care Planning for Paediatric Patients/ToolTip, Second Edition, 2008-02

Advance Care Planning for Paediatric Patients/ToolTip 2008-02 November 2008 700-56
Other Key Differences

Ethical Dilemmas in Pediatrics

Autonomy

- Potential for Conflicts
  - "family-centred care" fulfilled only by providing a comprehensive standard of care, which includes advance care planning
  - double-edged sword
  - family members may not share the same goals
  - early conversations may facilitate the grief process and family healing

- Third Party Respect for Autonomy / Impediments to Ethical Action
  - Schools and School Boards
  - concerns about lack of legal status and potential liability
  - lack of school policies and regulations, differing protocols
  - accepting, implementing, honouring family decisions
  - issue of intervention (non-intervention) while on school property
  - education for school boards, staff, other (private) schools
  - gap between when an child first experiences an incident and EMS arrival

- Emergency Medical Services (EMS)
  - Paramedics only recently authorized to withhold resuscitative measures
  - Ontario, 2008: introduction of executed DNR confirmation form authorizing paramedics or firefighters to honour patient wishes

Beneficence

- Do Good
- Ethical Obligation of Pediatric Health Practitioners: ACP Education
- Historic Pediatric Emphasis on Beneficence Over Autonomy
- Prima Facie Bias Toward Curative Over Palliative Options
- Optimizing Quality of Life

Other Key Differences

Ethical Dilemmas in Pediatrics

Non-Maleficence
- First, Do No Harm
- Carefully Considered Decisions
- Goal: Physician Comfort in Initiating Discussions with Children / Families
- ACP / Goals of Care Conversations are Not to be Prescriptive
- Slow, Careful Conversations to be Conducted with Sensitivity and Tact
- Repeated Review

Justice
- Weighing of Treatment Benefits and Burdens
- Setting of Death
- Resource Allocation
- Costs

For More Information & Goals of Care Resources:

- Visit the Advance Care Planning website
  www.calgaryhealthregion.ca/advancecareplanning
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Thank you.

Questions?