Advance Care Planning for the Neonate

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Session Summary
As perinatal palliative care develops, there is a need for advance care planning for the neonate to lift the child’s “voice” and determine what is most important to the child and family. Look to advance your neonatal palliative care skills beyond “comfort care” to support families with difficult and often times confusing decision-making. We will extract what’s known to be helpful from pediatric advance care planning documents to enhance neonatal advance care planning.

Session Objectives
Upon completion of this presentation, the participant will be able to:

- define neonatal advance care planning (ACP) and explain its value;
- describe tools used in ACP and perceived barriers to their implementation;
- explain how to initiate neonatal ACP conversations and who should be involved.

References
Aging with Dignity. http://www.agingwithdignity.org/5 Wishes/My Wishes


Advance Care Planning Background

- Adults experience unwanted interventions at end of life
- AHA produced statement (1974) declaring that CPR was not indicated for all patients
  - Patients with terminal and irreversible illnesses do not always merit CPR
  - In-hospital CPR prolonged pain/suffering
  - CPR out of hospital results in potential complications with concerns of ineffectiveness
  - Survival to discharge after out of hospital CPR < 10%
  - Significant impact on children with chronic complex conditions or life-limiting diagnoses

What is Neonatal ACP?

- "Value-Centered Care"
  - Elicit understanding, hopes, concerns, and QOL factors
  - Opportunity to make recommendations for care
  - Share burden parents face with decision-making
- Goals of Care context vs “Do you want us to do everything?”
- Process by which goals of care are clarified and treatment plans are c/w values and preferences

What is Neonatal ACP?

- Focuses on living, no matter how long and supports appropriate hopes
- “All on the same page”
- Not eliciting a particular decision (DNR) but informing on events that could occur and on reassuring that caring for the child will be the primary goal
What is Neonatal ACP?

Various Pediatric ACP Documents

- My Wishes (peds version of 5 Wishes)
- Wishes
- Voicing My Choices
- My Choices
- Respecting Choices/FACE (Family/Adolescent Centered advance care planning)
- Physician Orders for Life-Sustaining Treatments (POLST)

What is POLST?

- Developed in 1991 in Oregon by bioethicists
- Tool outlining current medical needs
- Address everything from invasive medical care to resuscitation status
- Wide degree of variability
- Broadest base of recognition and acceptance

POLST Map

Medical Orders for Life-Sustaining Treatment (POLST)

A6a: Advance Care Planning for the Neonate
Pediatric ACP

- Which population is this tool designed for?
  - Children with decisional capacity
  - Adolescents/young adults
    - Children without decisional capacity
- Where is the tool applicable?
  - Inpatient, outpatient, school
- Is this tool legally binding?
  - Some states POLST is legally binding for minors

Clinician Components of ACP

- Sanderson et al surveyed clinicians about components of ACP
  - Understanding of illness (75%)
  - Primary goals of parent (75%)
  - Understanding of prognosis (71%)
  - Belief system of family (22%)
  - Patient’s hopes (21%)
  - Patient’s perceptions of Quality of Life (20%)

Components of Neonatal ACP

- Clarity of Goals of Care
  - Duration of life, quality of life, minimizing pain/suffering, optimizing function, home-based
- Disease Status
  - Anticipated trajectory, complications
  - Prognosis and degree of certainty
- Treatments (Benefits/Burdens)
  - Medications
  - Potential symptoms and recommended treatments
  - Technology support
  - PT/OT/ST/MT
  - Triggers for medical attention
- Family/Financial Information

Components of Neonatal ACP

- Team Information
  - Contact information
- Emotional, Psychosocial, Cultural, and Spiritual issues
- Desired site of care
- Resuscitation status (be specific)
- Conditions under which treatment decisions might change (well vs not well)
- Participants in development of ACP
- Highlight any limitations of honoring plan beforehand
Components of Neonatal ACP

- If near death:
  - Memory-making
  - Legacy building
  - Location of death
  - Autopsy
  - Organ donation
  - Burial/Cremation
  - Funeral/Memorial services
  - Bereavement Follow-up
- Ideally, multiple meetings will be required

Birth Plan = ACP?

- Centered on Informed Consent
  - Difficult to make rational, responsible decisions without an understanding of complex medical outcomes (Kaempf)
- Components of Birth Plan
  - Establish understanding of diagnosis
  - Goals of care
  - Site/Mode of Delivery
  - Site of care mom’s room, NICU, home

Birth Plan = ACP?

- Components of Birth Plan
  - Resuscitation Status
  - Feeding Plan
  - Ceremonies/Baptism desired
  - Family Support/Memory-making
  - Postmortem Care
- Major “Difference” b/w Birth Plan & ACP – Dynamic
- Prenatal discussions and invitational conversation can help parents become engaged in decision-making

Who is involved in ACP?

- Trusted team member who is familiar with the family is the best person to introduce the process
  - Repeated discussions, Shared decision-making, Ensure continuity, Multiple family meetings
- Parents or legal guardians
- Lead physician/PCP/NNP & specialists
- Social worker, chaplain, OT/PT, CLS, etc
- Conversation can be led by physician, a team member, or another facilitator

When should ACP be initiated?

- ACP should take place with families at an opportune time and not just prior to death
- Soon after diagnosis
  - Unrealistic?
- Prenatal if possible
- During period of stability
- If there is a change in trajectory
- More frequent or more severe illnesses

When should ACP be initiated?

- Development of new comorbidity
- Clinical Triggers
  - Would you be surprised if this baby died within a year?
  - Would you be surprised if this baby died during this episode of care?
  - Do you know what the parents’ wishes are for end of life?
### Benefits of Adult ACP
- By normalizing end of life discussions, patients are given an opportunity to articulate their treatment preferences particularly if patients become unable to make decisions for themselves.
- Promotes autonomy and improves end-of-life care.
- Better rating of the dying experience.
- Enhance positive emotions and facilitate communication.

### Benefits of Pediatric ACP
- Parents need time for making decisions and preparing for their child’s death.
- Physicians can help parents improve decision-making by providing the opportunity to make decisions that are in accord with the family’s values/beliefs.
- Parents’ belief that they acted as a “good parent” is likely to be very important to their emotional recovery from the death (Hinds et al., 2010).
- More children die at home when planning and supports are available (Lotz et al., 2013).

### Adult ACP Barriers
- Belief ACP is “unnecessary” and only for the “elderly”.
- Uncertainty about own preferences.
- Desire to wait until situation arises.
- Desire to leave decisions to physicians.
- Wait on physicians to initiate.
- Document is difficult to use.
- Reluctance to discuss dying.
  - Greater information disclosure may actually support hope.

### Barriers of Pediatric ACP - Lotz
- Discomfort with document with unclear responsibilities.
  - Difficult for physicians to follow ACP.
- Uncertain prognosis.
- Physicians’ difficulties in initiating ACP.
  - Reluctance to discuss treatment limitations.
  - Perceived taboos.
  - Parents may scapegoat the initiator.
- Difficulties in identifying wishes.
  - Interpretation of non-verbal behavior.

### Barriers of Pediatric ACP - Lotz
- Burden for parents.
  - Actually signing ACP document.
- Limitations of ACP documents - Revocation.
- Lack of coordinated communication.
  - Complicated communication patterns.
  - Lack of “round tables”.
- Insufficient implementation within health care system.
  - Neglect of ACP in current practice.
  - Shortage of time (~2-3 meetings of 30-40 minutes).
  - Lack of funds for ACP.
Pediatric ACP Barriers

• Unpredictable trajectories – reluctance and uncertainty
  – Lack of diagnostic precision – Need earlier recognition of trajectory
• Clinicians not prepared to conduct conversations
• Lack of training
• Providers impose their own values on the family
• Emotional burden

• Durall et al surveyed clinicians finding these barriers:
  – Unrealistic parental expectations
  – Differences between understanding of prognosis
  – Parents’ unreadiness to have discussions
• Nurses identified lack of importance and ethical considerations more often
• 71% of clinicians believed ACP discussions happen too late
• Educational aims at knowledge, attitudes, and skills may help to address these barriers

Clinician Preparedness

• Sanderson et al surveyed clinicians about preparedness
  – 90% of clinicians felt prepared to discuss goals of care
  – 75% of clinicians felt prepared to participate in ACP
  – Several felt unprepared to discuss resuscitation status with school-aged (60%) or adolescent (48%)
  – 40% of clinicians believe that caring for patients with a poor prognosis is depressing

• Boss et al surveyed clinicians on recent mandate of MOLST in Maryland
  – 73% of physicians felt able to lead discussions “most” or “all” of the time
  – 75% of physicians led such a discussion in the past year
  – 55% of physicians had written no order to limit therapies in the past year

Clinician Perceptions of ACP

• Which patients? >80% of clinicians agree that limitation discussions were warranted only for children who were predicted to die within 30 days
• 58% of physicians felt MOLST would promote clear goals
• 15% of physicians felt MOLST might harm families by forcing difficult conversations
• 100% of parents thought all pediatric inpatients warranted MOLST discussions (only 17% of physicians)
• MOLST communication skills training was recommended by all

<table>
<thead>
<tr>
<th>Table 1. Clinician perceptions of life-sustaining treatments as indicated by MOLST form.</th>
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<tbody>
<tr>
<td>MOLST order form treatment</td>
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<tr>
<td>-----------------------------</td>
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<tr>
<td>Cardiopulmonary resuscitation</td>
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<tr>
<td>Resuscitation</td>
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<td>Intubation or mechanical ventilation</td>
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<tr>
<td>CPAP or BiPAP</td>
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<td>Feeding tube</td>
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<td>Central line</td>
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<td>IV fluids</td>
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<td>IV nutrition</td>
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<td>Blood transfusion</td>
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<td>Dialysis</td>
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<td>Hospital transfer</td>
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<td>Medical worship*</td>
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Clinician Perspectives on DNR

- DNR is not intended for prearrest state
- DNR in adults may decrease likelihood medical therapies may be initiated
- Sanderson et al surveyed clinicians regarding their attitudes and behaviors about DNR
- 67% clinicians believe DNR = limit resuscitation measures ONLY on arrest

Clinician Perspectives on DNR

- DNR indicates limitation of additional diagnostic and therapeutic interventions (52%)
- DNR order implies that comfort measures only are to be provided (6%)
- In reality, >85% believe that care changes beyond response to arrest, varying from increased attention to comfort (36%) to less clinician attentiveness (16%)
- Most clinicians reported that resuscitation status discussions take place later in the course than is ideal

Clinician Perspectives on DNR

- Sanderson et al concludes the variability in interpretation of DNR order may be due to:
  - Insufficient clinician education
  - Incomplete understanding of patient preferences
  - Lack of an appropriate tool

Clinician Discrepancies on DNR

- Clinicians do not “practice what they preach” - Lantos
- If DNR orders are used inappropriately as a proxy for goals, inappropriate withdrawal/withholding of treatments may occur
- 2 possible reasons:
  - Clinicians do not have the skills
  - Clinicians do not really believe the conventional wisdom about DNR orders

Parental Perceptions of ACP

- Wharton et al surveyed parents with children with special health care needs
- One in five had sufficient understanding of future medical needs and developmental potential
- 99% strongly agreed that physicians should share information no matter how upsetting
- 74% would consider written guidelines for their children that dealt with critical life situations

Parental Perceptions of ACP

- Parents of children would not survive - 94% wanted written guidelines
- Decisions are often constructed around singular medical event rather than a holistic view
- QOL judgements related to chronic health status are often overlooked and discussions start in PICU unfortunately
- Parents ultimately feel that ACP would be beneficial and wish to know all available options
Parental Perceptions of ACP

• Liberman et al surveyed parents of children with chronic illness in outpatient setting
• Previous ACP experience ~17%
• Interest in creating ACP document ~49% and was significantly more in families that had >ED visits in past year
  – Significantly less interest for children who had frequent admissions
• Given lack of knowledge but interest in pursuing ACP, there is an unmet need for children with chronic illness and an opportunity to enhance communication

Parental Decision-Making

• Parents desire active role
• Prefer collaborative > autonomous/paternalistic
• Parents want to be involved in end-of-life decisions
• Info from providers was the biggest influence for parents
• Wanting more time with their child or feeling they failed as a parent influences decision-making
• “Not giving up” is an important factor

Parental Perceptions of ACP

• Edwards et al evaluated ACP for children on long-term assisted ventilation with life-limiting conditions
• Retrospective review of ACP discussions for children who died
• Deaths in this population are unexpected and not the result of disease progression
• 21/47 children (45%) elected to forego resuscitation; 19/21 children had decisions occur in the acute setting
• 5/21 children had their DNR order rescinded after child improved (Survival Plateau)

“To add life to the child’s years, not simply years to the child’s life” - AAP

Questions?