Advance Care Planning and Directives for Children with Life-limiting Conditions

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Overview

- Population of children that benefit from Advance Care Planning.
- Discuss Advance Care Planning in context of progressive, irreversible illness and trajectory
- Review Texas Advance Directives Act, forms, purpose
- Discuss child, parent and health care provider roles, issues in developing Advance Care Plans

Who?

1. 7 y/o with early stage Duchene's Muscular Dystrophy
2. Term infant with congenital hydrocephaly
3. 6 y/o with newly diagnosed leukemia
4. 16 y/o with static encephalopathy, g-tube feeds, quadriplegia, and severe scoliosis
5. 2 y/o child abuse victim with traumatic brain injury in PICU

Complex Chronic Conditions of Childhood

- Medical condition reasonably expected to last at least 12 mos
- Involves several organ systems or one organ system severely enough to require specialty pediatric care and some period of hospitalization in a tertiary care center

Identifying the Population Served

Bexar County Estimates

<table>
<thead>
<tr>
<th>Children with Complex Chronic Conditions</th>
<th>Children with Special Health Care Needs</th>
<th>Population of Children Under 18</th>
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</thead>
<tbody>
<tr>
<td>432 (108 from CCC)</td>
<td></td>
<td>43,565 (2006 US Census)</td>
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<td>3397 – 7840 Hillegr &amp; Burnside, 2001</td>
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Medical Needs of Pediatric Sub-Populations

Primary Care

Medical Home + Risk screening Subspeciality care Comm. Services

Medical Home + Multiple Subspeciality Services Care Coordination Medical Decision Making Pain/Symptom Management

Medical Home + Multiple Subspeciality Services Care Coordination Medical Decision Making Pain/Symptom Management Spiritual Support, Grief and Bereavement Care

Healthy Child

CSHCN

Childhood CCC

Dying Child
Ilness Trajectories

- Wide variation across children with complex chronic illness
  - Healthy, sudden death
  - Illness - health crisis - sudden death
  - Chronic Illness – multiple health crisis, worsening, death
  - Chronic Illness – slow decline, intermittent health crisis, death
- Creates challenges in prognostication
  - The dying point?
  - 'Mis'-Prognostication (when we are wrong)
  - Uncertainty

Patterns of Hospital Use and Death

- Early 90's first look at how/where children die
  - 25% of deaths due to CCC
  - For infants 92% of all days of life were spent in hospital
  - Among children and young adults 55% hospitalized at time of death, 19% ventilated
  - Stable to slight increase in death rates in infancy late adolescence, decrease in childhood years
  - Rate of hospital use increased as death drew near

Deaths In ICU

- Several studies published in early 1990's
  - Discussions and decisions related to limitation of non-beneficial interventions occurred in 30% to 58% of patients in PICU
- NICU data 1987-88
  - Discussions and decisions related to limitation of non-beneficial interventions occurred in 22% of patients

Characteristics of Death from CCC

  - 2000 HCUP-KID review
  - 56% to 61% occur in Hospital, 86% in ICU
  - CCCC more likely to die in Children’s Hospitals with longer LOS (10 days) and costs of ~$100,000
  - General Hospital deaths primarily non CCC, shorter LOS (50% on day of admit) at ~$34,000
  - Most prevalent CCC categories: <12 mos cardiovascular, respiratory, congenital/genetic 10-18 yrs Neuromuscular, malignancies

A Decade of Pediatric Palliative Care

- Significant increase in PPC programs, literature, curriculum, and professional groups.
- Changes in outcomes for children
  - Feudtner (2007) – Significant increase in home deaths
  - Lee et al (2010) – Increase in limitation of non-beneficial medical interventions in PICU (>50% in all institutions)
  - Hagen et al (2004) – Increase in limitation of non-beneficial medical interventions in NICU (63.5%)

A decade of Pediatric Palliative Care

- Limitation of non-beneficial interventions
  - significantly increased in training institutions
  - Azoulay (2007) limitation correlated with higher number of nurses per bed, but inversely related to presence of ED, and in house ICU docs
  - Both Lee and Fruedtner studies showed racial disparity in measured outcomes
Medical Decision-Making

- Children with CCC face many difficult decisions during the illness trajectory
- Medical professionals and parents must develop a plan for care based on:
  - Anticipated disease, illness trajectory
  - Overall prognosis
  - Current level of functioning, quality of life
  - Sudden, acute illnesses with "real time" decision making

Ethical Decision Making

- Identify the ethical challenge
  - Ventilation of neurodegenerative disorders
  - Ongoing treatment of refractory cancer
- Gather the facts
- Consider values/beliefs of individuals involved
- Look for consensus/balance
- Develop options based on particular circumstance.

Four Box Method

- Medical Indications
- Patient Preferences
- Quality of Life
- Contextual Factors

Jonsen, Siegler, and Winslade (2006)

Ethical Decision Making

- Best Interest Standard
  - When, How applied?
  - Who determines the child's best interest:
    - Parent
    - Health Care Team
    - Ethics Committee
    - Judges
  - Better frameworks?
    - Harm Standard
    - Phronetics

Ethical Decision Making

- Substituted Judgment
  - Occurs when others decide for a patient that is not competent
  - Children are not legally competent to make medical decisions
  - Role of child in determining preferences for medical care:
    - Raises issues in verbal children and adolescents
    - Assent
    - Professional, Parent, Child conflict

Non-EOL Treatment Decisions

- Non-EOL Treatment Decisions
  - Complex medical/developmental conditions lead to a variety of difficult non-EOL settings
  - Respiratory Support in neurodegenerative conditions
  - Elective surgeries
  - Nutrition/Hydration
  - Growth Attenuation (Ashley treatment)
  - Reproductive issues
Ethical Decision Making

- Involving Children in Medical Decision Making
  - Developmental Considerations
  - Family Considerations
  - Provider Considerations

Communication

- Conversation vs. informing
- Talking vs. Listening
- Receptive vs. Expressive
- Verbal vs. Non-verbal
- Honesty, Respect
- Clinical vs. everyday language; jargon

Communication

- Role of relationship based care
  - Illness experience
  - Shared decision making

Understanding Parental Decision Making

- Different basis for decisions
- Logically illogical?

Understanding HOPE

- Conditioned Response
- Source of Strength/Resilience
- Detriment

Advance Care Planning

- Dynamic process over time
- Identifies concerns of child/family
- Focused on anticipatory guidance through trajectory, preferences for care
- Advance planning allowing for real time decision making

Integrative Pediatric Palliative Care

- Family Centered Care optimized for children with Complex Medical Conditions
  - Shared decision making
  - Focused on illness experience, family values
  - Establishes understanding of prognosis, goals of care
  - Attention to sources of preventable suffering
  - Multifaceted, Transdisciplinary
Advance Directives Legislation

- **1999 revision**
  - Texas Advance Directive Act
    - Directive to Physician (allows for request and refusal)
    - Medical Power of Attorney
    - Out of hospital DNR
    - Medical Futility
  - 2003 Revisions
    - Influenced by Baby Doe Regulations
    - Made clear the legislation applied to minors
    - Clarified OOH as an EMS document and allowed other community health care providers to recognize a physician DNR order

Important Terms

- **Irreversible Condition**
  - A condition, injury, or illness that may be treated but is never cured or eliminated
  - Leaves a person unable to care for or make decisions for that person's own self
  - Without life sustaining treatment provided in accordance with prevailing standard of medical care, is fatal

- **Terminal Condition**
  - An incurable condition caused by injury, disease, or illness
  - In reasonable medical judgment will produce death in 6 months even with available life-sustaining treatments

Important Terms

- **Artificial nutrition and hydration**
  - Provision of nutrients or fluids by a tube inserted in a vein, under the skin, or through a tube in the stomach

- **Cardiopulmonary Resuscitation**
  - Medical intervention to restore circulatory or respiratory function that has ceased

- **Life Sustaining Treatment**
  - Treatment, based on reasonable medical judgment, sustains the life of a patient and without which the patient will die.
  - Includes both life-sustaining medications and artificial life support such as ventilators, dialysis, artificial nutrition and hydration
  - Does not include pain management medications or medical procedures considered necessary to provide comfort care

Components of Advance Directives

- **Directive to Physician**
  - Instruction to administer, withhold or withdraw life-sustaining treatment in the event of a terminal or irreversible condition
  - Parent, spouse or legal guardian may give directive for child <18
  - Does not require physician signature, notarization, or a specific form
  - Adults may give verbal directive in presence of physician and two witnesses, does not speak to children
  - Excludes withdrawal/withholding in pregnant patient
Directive to Physician

- Use in Pediatrics
  - Not widely used
    - Wide variability in disease/condition management options
    - Uncertainty of prognosis in many situations
    - Role of comfort and QOL
    - Parent need for 'real time' decision making in dynamic disease progression

Components of Advance Directives

- DNR
  - Out of Hospital DNR
    - Legally binding document directing health care professionals in out-of-hospital settings not to initiate or continue certain LST
    - DOES NOT include authorization to withhold medical interventions or therapies necessary to provide comfort care, alleviate pain or provide water/nutrition.
    - Must use Standard State Form, may be a photocopy
    - Parent, spouse or legal guardian may execute for child <18

Revocation

- Directive to physician and DNR may be revoked at any time by the adult patient or guardian of a minor
  - May be done verbally, in writing, or by destroying documents
  - Patient desire supersedes Directive, including patient under age of 18

Liabilities

- H&S Code
  - 166.044 Limitation of liability for withholding, withdrawing LST
    - Limits civil liability for physicians, other health care professionals and facilities acting in good faith and within prudent standards of care
  - 166.047 Honoring directive does not constitute aiding suicide
  - 166.050 Mercy killing not condoned
    - Does not allow for euthanasia or assisted suicide

Disagreement regarding Medical Treatment

- Procedure for not effectuating a Directive or Treatment Decision
  - Process outlined in 166.045
    - Physicians refusal will be reviewed by facility ethics committee
    - Physician may not be a member of that committee
    - LST will continue during review
    - Patient/surrogate may attend and will receive a written explanation of the committee decision
    - If disagreement continues – all reasonable efforts will be made to transfer care to another physician/facility willing to honor wishes. LST continues during this process.
    - If no accepting facility – may go through court proceedings

The Debate over Futility

- 2009 and 2011 legislation
  - Challenges to Futility portion of TADA
  - Contemporary cases involving children with life limiting issues
    - Child in Austin – Leigh Disease, toddler
    - Child in Houston – Brain Tumor, adolescent
  - Would remove the time limitation for families to find an accepting facility to continue treatment
  - Change from 1977 – families insisting on life-sustaining treatment, HCP indicating futility
The Debate over Futility

- How to Define Futility
- Professional Autonomy
- Parent/Family Autonomy

Important Terms

- Non-Beneficial Medical Interventions
  - Interventions that do not reverse, palliate or improve a patient's condition
  - ?Useless
- Futility
  - Failure of effective communication and decision making?
  - Families with unrealistic expectations?
  - Medical futility laws - legal process

Wrap-up

- Multiple challenges in managing care for children with complex medical needs
- Ethical, Social, and Political challenges will continue to influence approaches to care
- Systems of care that promote continuity and legal process

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Questions? Concerns?

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