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

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Overview

- Population of children that benefit from Advance Directives.
- Discuss Advance Directives in context of progressive, irreversible illness; trauma
- Review Advance Directives law, forms, purpose
- Discuss child, parent and health care provider roles, issues in developing Advance Directives

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Which child would most likely benefit from advanced care planning and directives?

1. 12 y/o with early stage Duchene’s Muscular Dystrophy
2. Term infant with congenital hydrocephaly
3. 6 y/o with end stage 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

Prevalence of CSHCN

- 6.5% of children in US experience some level of disability due to CSHCN
- Annual Impact of CSHCN in childhood
  - 66 million restricted activity days
  - 24 million days lost from school
  - Additional 26 million physician contacts
  - Additional 5 million hospital days

Newacheck & Hallo, 1998 Am J of Pub Health

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State of Texas Estimates

Population of Texas Children

- Child Deaths: Extrapolated as percent of US rates
  - 4723 (x, y, z)
- Children with Complex Chronic Conditions: 111,724*
- Children with Special Health Care Needs: 752,667*
- Child Deaths: Extrapolated as percent of US rates
  - 4723 (x, y, z)
- Population of Texas Children: 5,880,213 (US CB, 2000)

Medical Needs of Pediatric Sub-Populations

- Healthy Child
- Medical Home + Risk screening, Subspecialty care, Comm. Services
- Childhood CCC
- Medical Home + Multiple Subspecialty Svc, Care Coordination, Medical Decision Making, Pain/Symptom Management
- Dying Child
- Medical Home + Multiple Subspecialty Svc, Care Coordination, Medical Decision Making/Advanced Directives, Pain/Symptom Management, Spiritual Support, Grief and Bereavement Care

Illness Trajectories

A: Sudden Onset
   - Remission
B: Steady Decline
C: Fluctuating Decline
D: Fragile

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Patterns of Hospital Use and Death

- Feudtner et al 2003
  - Deaths in Washington State 1990-1996
    - 25% of all deaths were 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
    - Rate of hospital use increased as death drew near

Patterns of Hospital Use and Death

- Trends in death from childhood complex chronic conditions
  - U shaped curve
  - Stable to slightly increased mortality rates in infancy and adolescents/young adults
  - Decline in deaths occurring in mid-childhood

Characteristics of Death from CCC

  - 2000 HCUP-KIDS database review
  - 56% to 61% occur in Hospital, 86% in ICU
  - CCC 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
Medical Decision-Making

- Children with CCSHCN face many difficult decisions during the illness trajectory

- Medical professionals and parents must develop plan for care based on:
  - Anticipated disease, illness trajectory
  - Overall prognosis
  - Current level of functioning, quality of life
  - Sudden, acute illnesses

Integrative Pediatric Palliative Care

- Family Centered Care optimized for children with Complex Medical Conditions
- Focused on promoting quality of life through enhanced communication and medical decision making based on individual child and family values.
  - Shared decision making
  - Focused on illness experience, family values
  - Establishes understanding of prognosis, goals of care
  - Attention to sources of preventable suffering
  - Multifaceted, Transdisciplinary

Integrative Care
Ethical Decision Making
- Identify the ethical challenge
- Gather the facts
- Consider values/beliefs of individuals involved
- Look for consensus/balance
- Develop options based on particular circumstance.

Characteristics of Death from CCCC
- Shift in Place of Death
  - Fuedtner, 2007
  - National Center for Health Statistics Death Data 1989-2003
  - Significant increase in home death for CCCC
  - Odds increased significantly each year
  - Significant racial & ethnic disparities noted
    - Black, Hispanic CCCC less likely to have home death

Case Study
- 2 y/o with congenital brain malformation
- Sister died at age 4 of same condition
- Patient now has worsening feeding with aspiration noted on swallow study.
Advance Directives

Texas Health & Safety Code – Chap 166
  – Texas Natural Death Act
    - Originally enacted 1989, w/ subsequent revisions
    - Allowed for process for individuals to communicate their wishes for health care in event of irreversible or terminal illness – surrogate decision-makers
    - Legal issues at the time prompted many states to establish such legislation
      - Quinlan, Cruzan
      - Both cases involved removal of artificial nutrition/hydration

Important Terms

Irreversible Condition -
  - 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 –
  - 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

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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

- **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

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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

Important Terms

- Non-Beneficial Medical Interventions
  - Interventions that do not reverse, palliate or improve a patient's condition
  - Preferred term over Futility

- Futility
  - Failure of effective communication and decision making
  - Families with unrealistic expectations
  - Medical futility laws - legal process

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
Case Study

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Four Box Method

Jonsen, Siegler, and Winslade (2006)

Medical Indications

Patient Preferences

Quality of Life

Contextual Factors

QUESTIONS?

CONCERNS?