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

Melody Brown Hellsten, RN, MS, PNP-BC

Melody Brown Hellsten, RN, MS, PNP-BC
has no relevant financial relationships with commercial interests to disclose.

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

This presentation is the intellectual property of the author/presenter. Contact them for permission to reprint and/or distribute.

- 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

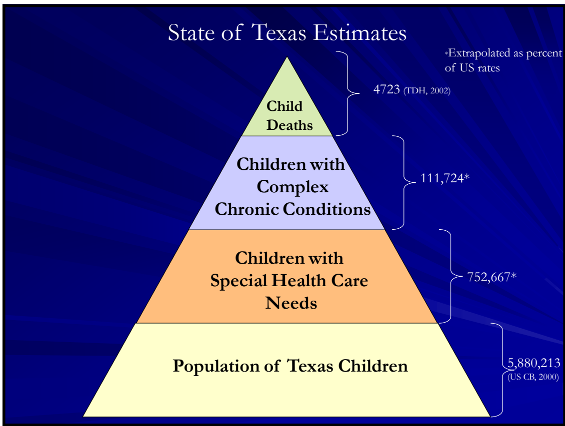
Feudtner, Digiuseppe, Neff 2003. BCM Medicine

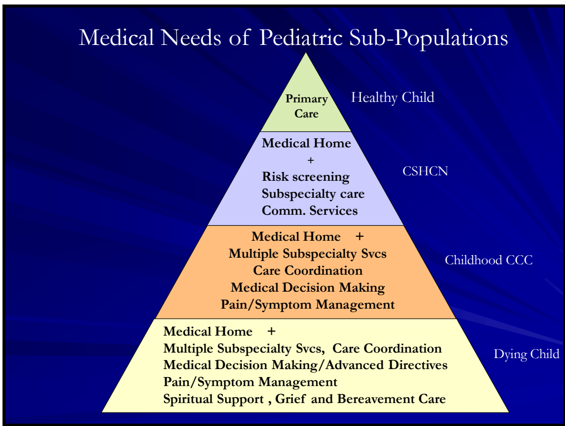
Prevalence of CSHCN

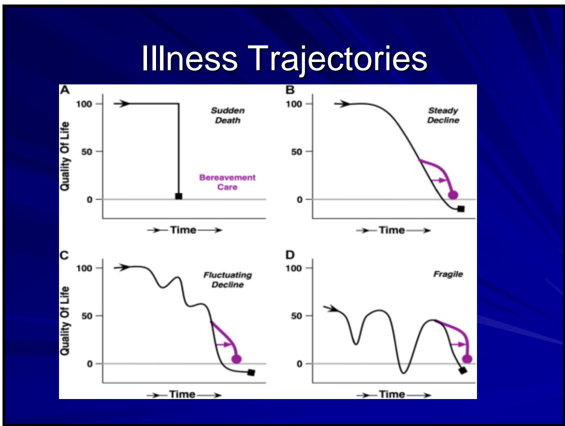
- 6.5% of children in US experience some level of disability due to CSHCN
- Annual Impact of CSHCN in childhood
  - 66 million restricted activity days
  - 24 million days lost from school
  - Additional 26 million physician contacts
  - Additional 5 million hospital days

Newacheck & Halfon, 1998 Am J of Pub Health

This presentation is the intellectual property of the author/presenter. Contact them for permission to reprint and/or distribute.







This presentation is the intellectual property of the author/presenter. Contact them for permission to reprint and/or distribute.

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

Feudtner, Hays, Haynes,et al, 2001, Pediatrics

Characteristics of Death from CCC

- Brandon et al J Palliative Med, 2007
  - 2000 HCUP-KIDS database 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

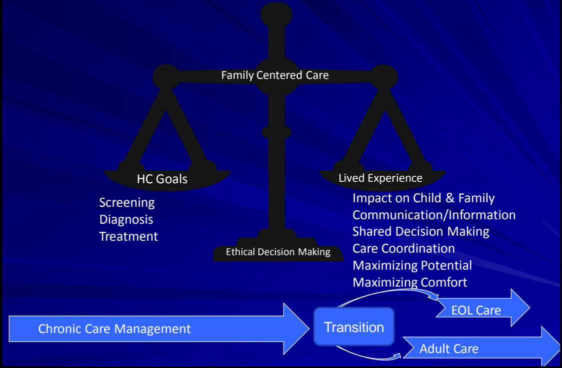
This presentation is the intellectual property of the author/presenter. Contact them for permission to reprint and/or distribute.

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



This presentation is the intellectual property of the author/presenter. Contact them for permission to reprint and/or distribute.

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
    - Natl 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.

This presentation is the intellectual property of the author/presenter. Contact them for permission to reprint and/or distribute.

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

This presentation is the intellectual property of the author/presenter. Contact them for permission to reprint and/or distribute.

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

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

This presentation is the intellectual property of the author/presenter. Contact them for permission to reprint and/or distribute.

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 patients 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

This presentation is the intellectual property of the author/presenter. Contact them for permission to reprint and/or distribute.

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.

Four Box Method

Jonsen, Siegler, and Winslade (2006)

Medical Indications	Patient Preferences
Quality of Life	Contextual Factors

QUESTIONS? CONCERNS?

This presentation is the intellectual property of the author/presenter. Contact them for permission to reprint and/or distribute.