Perinatal/Neonatal Palliative Care

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Objectives:

1. Define palliative care and the role of an interdisciplinary team in neonatal and perinatal patients
2. Identify appropriate neonatal and perinatal palliative care consults
3. Discuss parental decision-making when navigating various clinical pathways

But first…

- palliative care PSA

Pediatric Palliative Care works to…

- Prevent/relieve the symptoms produced by a chronic, complex and/or life-threatening medical condition or its treatment
  - Aggressive **Symptom Control**
- **Live as *normally* as possible** by addressing physical, emotional, social, practical, spiritual, developmental, and educational **domains of suffering**
- Provide them with timely and accurate **information** and support in **decision-making**

WHAT IS PALLIATIVE CARE REALLY?

- Organized system of holistic care for children with *chronic*, *complex* and/or *life-threatening* conditions and their families
  - May live a long time with severe debilitating chronic illness
  - May ultimately be cured but for whom the journey will be difficult
  - May be dying or may die soon
- Focus is on symptom relief, quality of life, empowerment/mastery, and intactness of self and family

Essentials of Palliative Care

- Combined with cure-oriented, disease-modifying, life-prolonging therapy, **not either/or**
- Holistic care for a patient who is not going to “get better”
- Family/Patient-Centered
- Prevent/relieve suffering of **living and dying**
- Empathic and culturally-sensitive support
- Developmentally appropriate

Early Palliative Care Effect

- Methods
  - Randomly assigned patients with newly diagnosed metastatic NSCLC to receive either:
    - Early palliative care integrated with standard oncologic care
    - Standard oncologic care alone
  - QoL & Mood were assessed at baseline and at 12 weeks
  - Primary outcome was change in QoL at 12 weeks
  - End of life data was extracted from medical record

Temel J et al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *NEJM*. 2010; 363(8):733-42

Early Palliative Care Effect

- Background
  - Patients with metastatic non-small-cell lung cancer have substantial symptom burden
  - Patients may receive aggressive care at end of life
  - Evaluated the effect of early palliative care after diagnosis on patient-reported outcomes and end of life care

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Early Palliative Care Effect

- Results
  - Better QoL in Early PC group (P=0.03)
  - Fewer depressive symptoms in Early PC group (16% vs. 38%, P=0.01)
  - Fewer Early PC group patients received aggressive end of life care (33% vs. 54%, P=0.05)
  - **Median survival was longer for Early PC group** (11.6 vs. 8.9 months, P=0.02)
- Conclusion: Early Palliative Care improved QoL & mood with less aggressive care at end of life but longer survival

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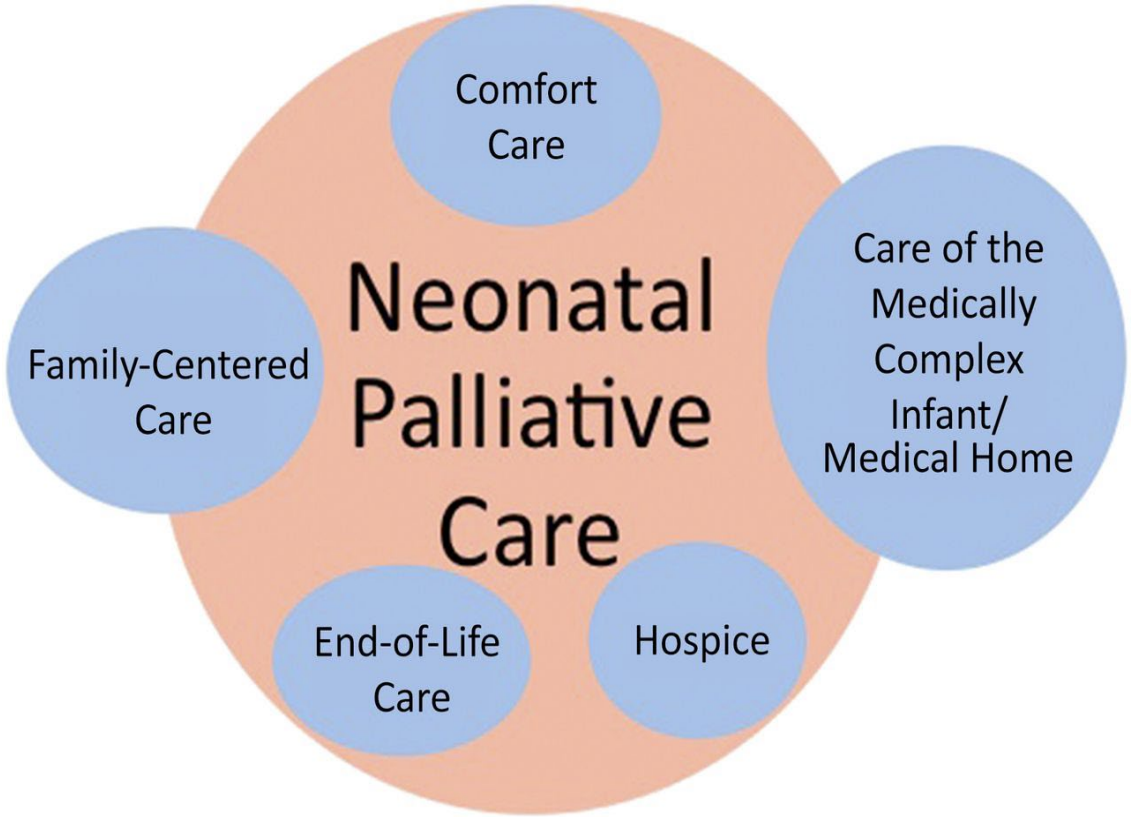
Palliative Care in NICU

- Slow adoption
  - Uncertainty in terminal prognosis
  - Difficulty moving away from interventionist approach
  - Divergent caregiver perceptions of the “right” action
  - Degree of moral and legal ambiguity
  - Fear of “lingering death”
  - Different specialty agendas
  - Lack of formal training and experience

https://www.youtube.com/watch?v=5Xgt-x9KVwE

PALLIATIVE CARE in NICU

- When should we involve palliative care?
  - Congenital anomalies incompatible with life or potentially life-limiting conditions
  - Newborns born at limits of viability
  - Infants with overwhelming illness not responding to life-sustaining intervention
  - What about other NICU patients? Prenatal involvement?

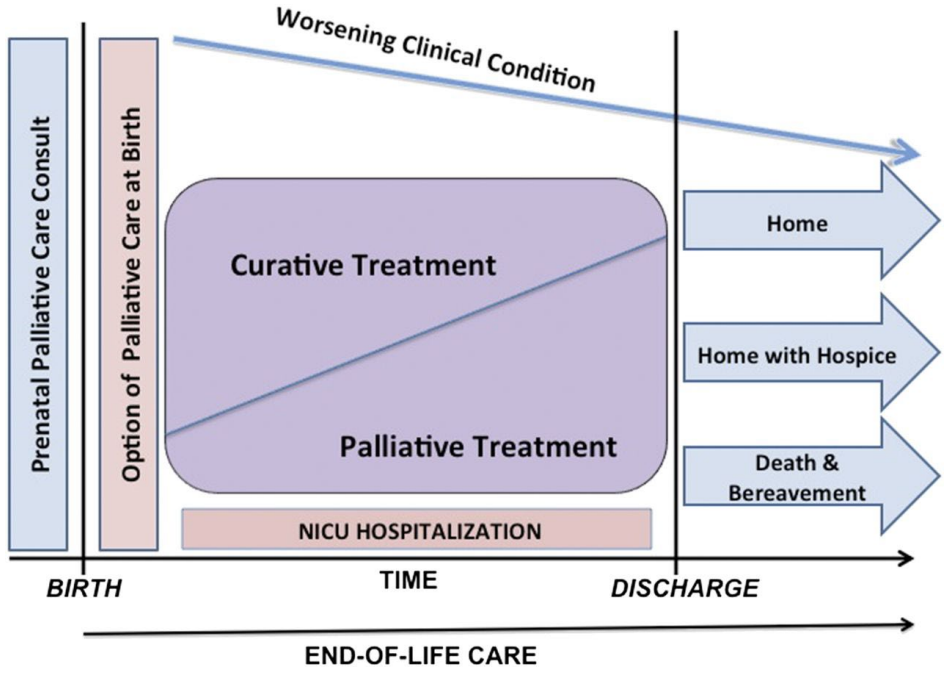


NICU – Role of Palliative Care

- Processing medical information
- Assistance with medical decision-making
- Goals of care
  - Pursue disease-modifying intervention: surgeries or additional long-term technology
  - Redirection of care with discontinuation of no longer beneficial life-sustaining treatments/technologies
- Advance care planning, if applicable
- Pain and symptom management
- Care coordination

Palliative Care in NICU

- A family-centered, integrated, culturally driven plan of care to support families
- Make the families and neonates as comfortable as possible
- Palliative and bereavement care must be considered as standards of care and treated as expectations, not as optional additional services
- Support to staff caring for these patients/families



Myths About Palliative Care

- Palliative care hastens death
- Palliative care = hospice/end of life care/comfort care
- Palliative care means “giving up” or “losing hope”
- Palliative care begins when curative treatments stop
- DNR means “do nothing”

Language of Pediatric Palliative Care

- Helpful Phrases
  - Let's talk about the labs (or interventions/treatments) that are not providing benefit for your child and talk about discontinuing these
  - Let's review what we have done so far, what has been the outcome, and what are our goals of care
  - In my experience, I have not seen a child in this situation survive. We will continue to hope for his comfort and quality time with those who love him
  - What are your hopes for your child?
  - We are in a different place…

What is Perinatal Palliative Care?

- Perinatal palliative care refers to a coordinated care strategy that comprises options for obstetric and newborn care that include a focus on maximizing quality of life and comfort for newborns with a variety of conditions considered to be life-limiting in early pregnancy.

National Statistics

- Approximately 3% of pregnancies have a potentially life-limiting fetal diagnosis.
  - Of those pregnancies, 20-40% of women are continuing their pregnancy when supported by a multidisciplinary team with perinatal palliative care.
- In the United States, more than 1 million children are living with chronic conditions.

The Role of Perinatal Palliative Care

- Build rapport
- Explore family values
- Assess parental understanding
- Provide assistance with medical decision-making
- Assist with care coordination
- Provide emotional support
- Continuity of care

Interdisciplinary/Multidisciplinary Approach

- Physicians, NPs, PAs
- Counselors
- Social workers
- Chaplains
- Patient navigators
- Child life specialists
- Music therapists
- OB, MFM, NICU teams
- Pediatric specialists
- Genetic counselors

Barriers to Palliative Care Consultation

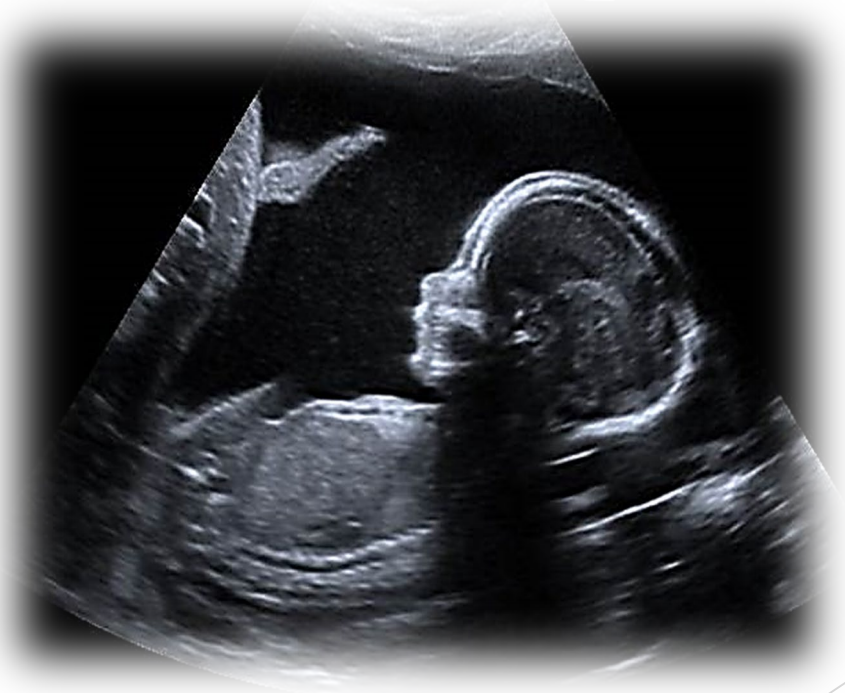
- Lack of diagnostic and prognostic certainty
- Referral Hesitancy
- Family Reluctance
- Late referrals

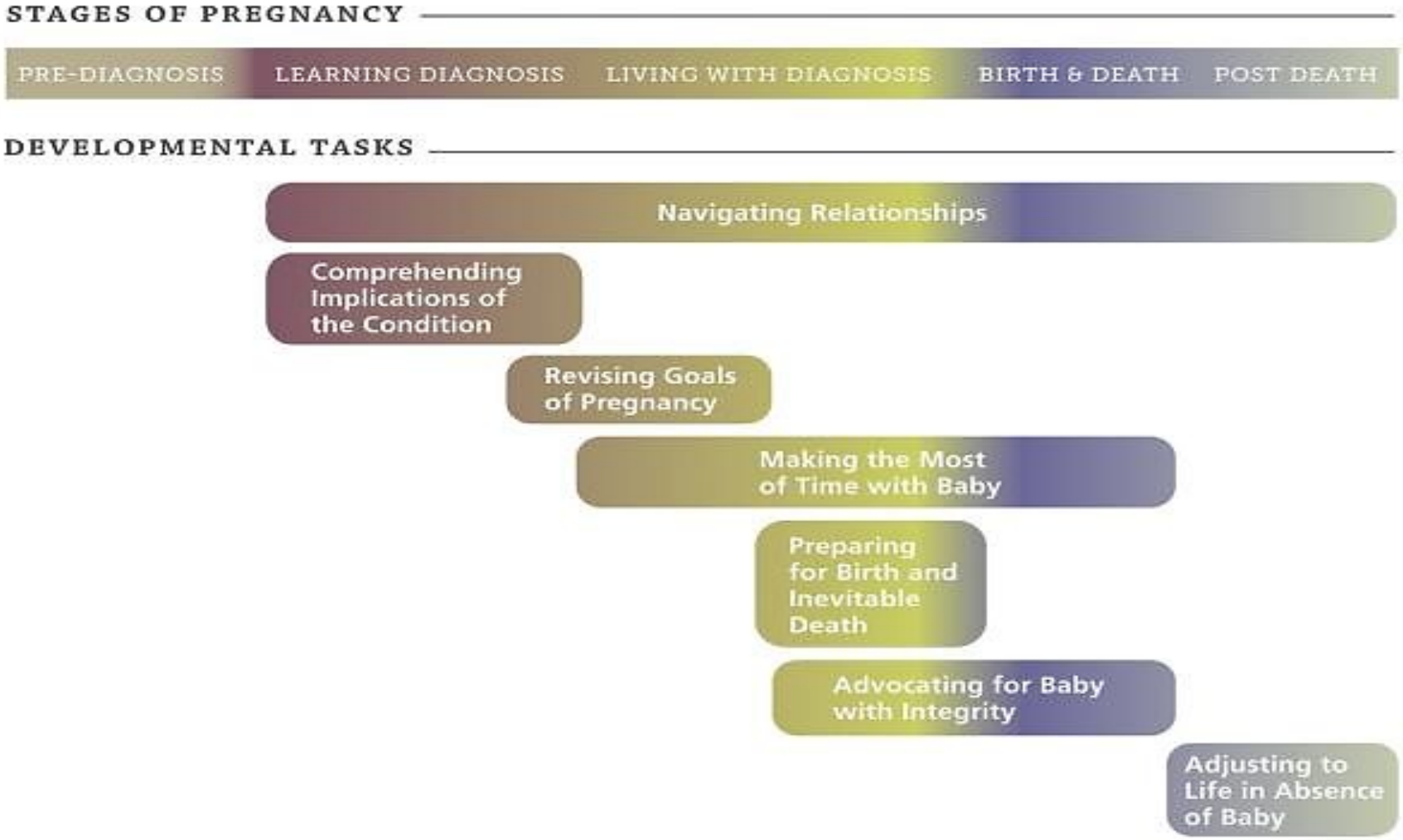
Appropriate Perinatal Palliative Care Diagnoses

- **Genetic**
  - Trisomy 18, 13, Triploidy, & other major genetic abnormality w/ severe anomalies
- **Cardiac**
  - Single ventricle cardiac defects
- **Congenital anomalies**
  - Omphalocele (severe), Limb-body wall complex, Pentalogy of Cantrell
- **Neurological**
  - Any brain reduction CNS anomalies (Lissencephaly, Hydranencephaly), anencephaly/holoprosencephaly, encephalocele, severe congenital hydrocephalus, meningomyelocele (severe)
- **Renal**
  - Bilateral multicystic dysplastic kidney disease, bilateral renal agenesis
- **Pulmonary**
  - Congenital diaphragmatic hernia, severe congenital pulmonary airway malformation w/ consideration of fetal intervention, tracheal agenesis
- **Other**
  - Hydrops, extreme prematurity (22-24 wga), conjoined twins

Parental Response to Life-Limiting/Life-threatening Fetal Diagnosis

- Anticipatory grief
- Process diagnosis and prognosis
- Evaluate goals of care
- Shared decision-making




STAGES OF PREGNANCY
PRE-DIAGNOSIS
LEARNING DIAGNOSIS
LIVING WITH DIAGNOSIS
BIRTH & DEATH
POST DEATH
DEVELOPMENTAL TASKS
Navigating Relationships
Comprehending Implications of the Condition
Revising Goals of Pregnancy
Making the Most of Time with Baby
Preparing for Birth and Inevitable Death
Advocating for Baby with Integrity
Adjusting to Life in Absence of Baby
OVERALL GOAL
No Regrets

Parental Decision-making

- Maternal age
- Spiritual beliefs
- Fetal prognosis
- Perceptions of uncertainty
- Timing of fetal diagnosis
- Cultural values
- Parental loss history
- Socioeconomic status
- Fear of having regrets
- Quality of life concerns

Language Matters

- Phrases to avoid:
  - Lethal
  - Incompatible with life
  - Futile
  - Would you like us to do everything?
  - Withdrawal of care
  - You’re so strong
  - We will take care of your baby as if they were our own child

Language Matters (continued)

- Recommendations:
  - Match parents' terminology (fetus, baby, baby's name)
  - Ask about hopes, fears, goals
  - Reflect to parents' views
  - Ask open-ended questions and tolerate silence
  - Validate emotions
  - Put your own biases aside
  - Provide concise information, without giving a sense of hopelessness

Clinical Pathways in Perinatal Palliative Care

- Life-limiting – no possibility of a cure
  - Palliative care should be consulted at time of diagnosis
- Life-threatening – there are potential curative treatments
  - Palliative care should be consulted prenatally to provide support following delivery, in the acute phase and if curative treatment is no successful

Termination of Pregnancy

- Fetus has a life-limiting diagnosis
- Role of Palliative Care
  - Assistance with medical decision-making
    - MFM/OB presents option of termination of pregnancy
    - Palliative care can explore possibility of continuing pregnancy
  - Bereavement support

Birth Vision Development

- Fetus has a life-limiting diagnosis
  - Family goals:
    - 1. comfort measures only (avoiding invasive interventions) provided at the mother's bedside to allow a natural death
    - 2. May consider time-limited trial of non-invasive and/or invasive interventions with frequent re-evaluation of goals

Palliative Care Role in Birth Vision Development

- Processing medical information
- Exploration of goals of care and/or advance care planning
- Assistance with medical decision-making
- Care coordination
  - Collaboration with inpatient and outpatient teams (MFM, OB, NICU, Peds specialists) regarding upcoming delivery
  - Coordinate consults and memory-making: music therapy, chaplains, NILMDTS, child life
- Provide psychosocial support
- Bereavement support

NICU Pathway

- Fetus has a life-threatening diagnosis and is expected to survive following delivery
- Family goals:
  - 1. Full resuscitative efforts in the delivery room with admission to the NICU
  - 2. A trial of medical interventions with possible redirection of care, pending clinical response

Psychosocial Support

- Assessment of emotional and psychosocial distress
- Exploration of family dynamics
- Evaluation of economic resources
- Provides ongoing support to parents and extended family members.

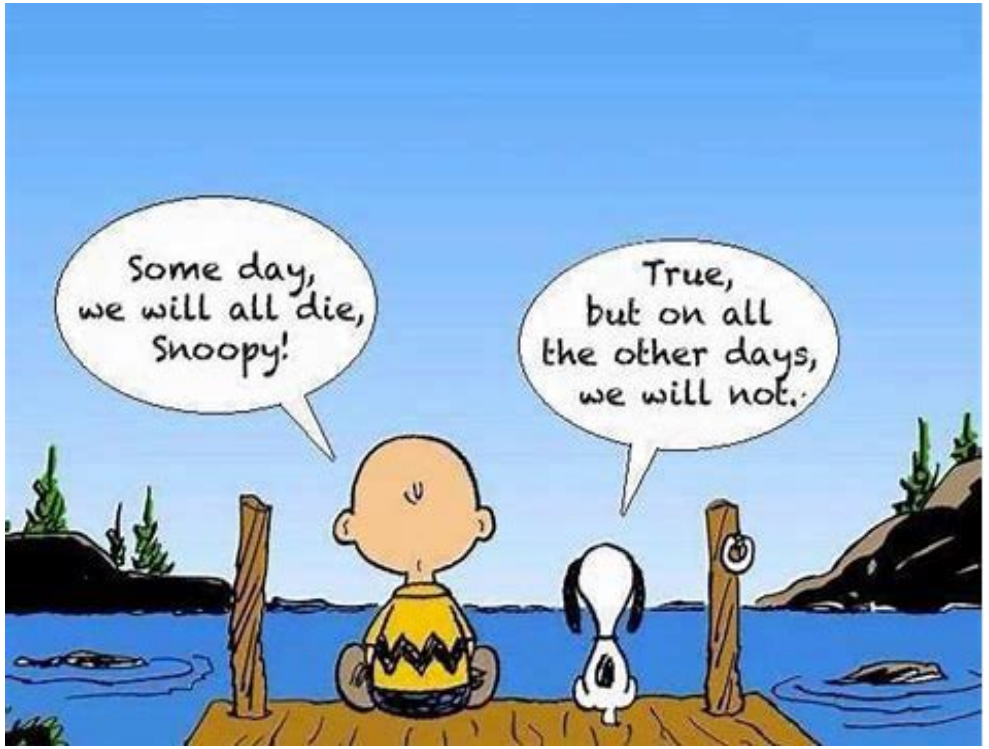
Grief

- The death of a child is one of the most excruciating life experiences for a parent
- When psychological symptoms are not adequately addressed, it can negatively impact their health and interpersonal relationships
  - 25% of bereaved parents report new chronic illnesses
  - Increased mortality risks
  - Feelings of isolation, absence of close relationships, increased marital strain and even divorce

Thank you!

"To add life to the child's years, not simply years to the child's life" - AAP

"Dying doesn't cause suffering. Resistance to dying does." – Ira Byock



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