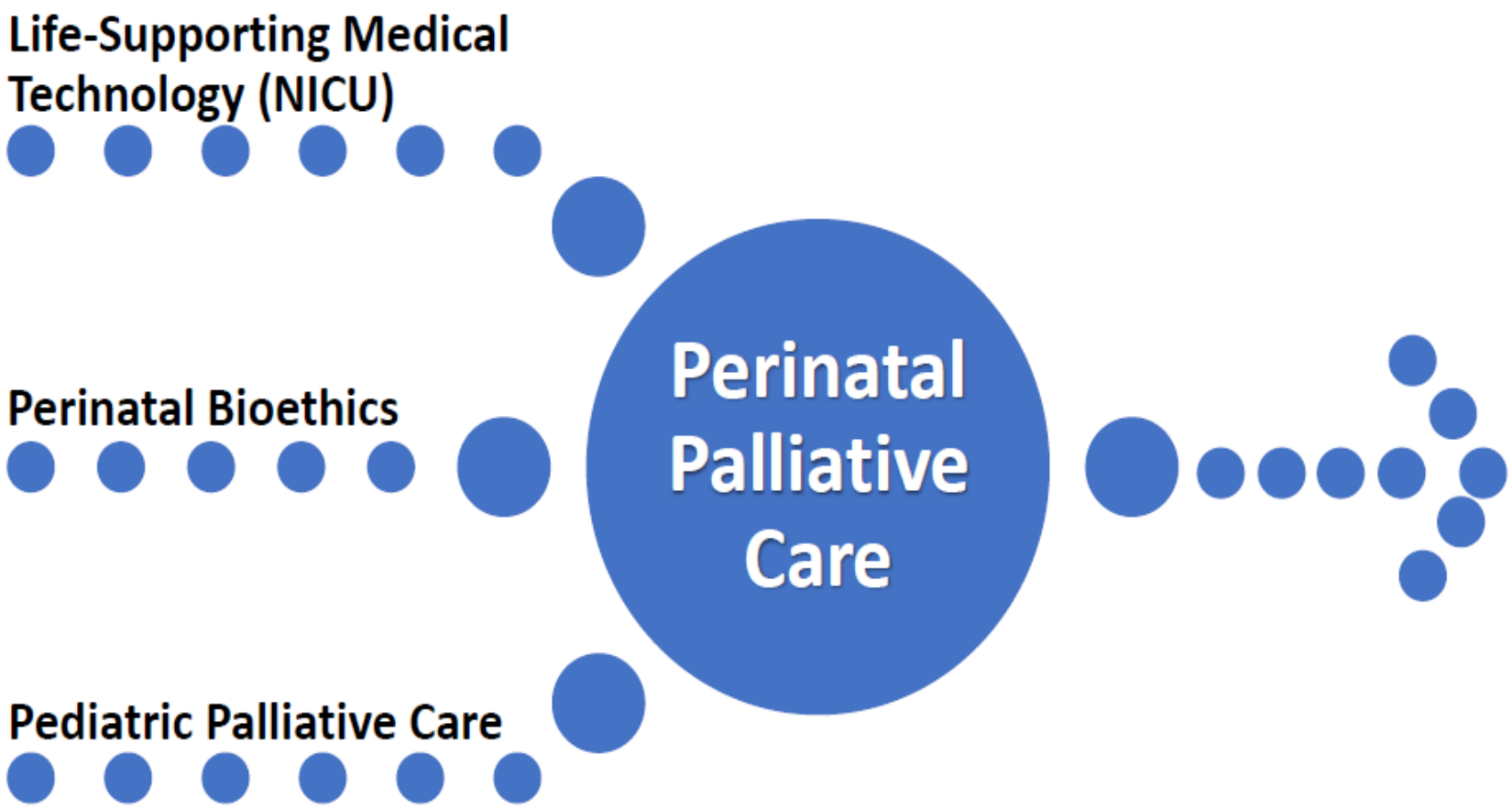
Evolution of Perinatal Palliative Care

BRIAN S. CARTER, MD, FAAP
PROFESSOR OF PEDIATRICS (NEONATOLOGY)
CHAIRMAN, AND SIRRIDGE ENDOWED PROFESSOR
DEPARTMENT OF MEDICAL HUMANITIES & BIOETHICS
THE UNIVERSITY OF MISSOURI-KANSAS CITY, SCHOOL OF MEDICINE
INTERIM-DIRECTOR, CHILDREN'S MERCY PEDIATRIC BIOETHICS CENTER
EMAIL: BSCARTER@CMH.EDU

The Evolution of Perinatal Palliative Care



*** Work by Whitfield, et al. in 1980s and by Calhoun & Hoeldtke in 199**

Prenatal Diagnoses & Counsel

- The pregnancy narrative
- Goals & values
- Birth plan

Delivery Room Presence & Support

- Psycho-social-spiritual
- Being present

Post-Delivery Care

- NICU
- Nursery
- Home

First: Remember the Uniqueness of Pregnancy Among Human Experiences

- **This will guide you in your *empathy***
  - Partner with parents & their hopes
- **Realize *dreams* may be shattered**
  - With a concerning fetal diagnosis or critically ill newborn
- ***Parental fulfillment* is challenged**
  - Motherhood, womanhood, parenting
- ***Joy* may be lost**

Before, or After, Birth… Things Change

Wonder ➔ Catastrophe

Individuality ➔ Categorization

Personalize ➔ Objectify

Encourage ➔ Obsess

Perinatal & Pediatric Palliative Care 2022

We still encounter the following myths expressed by the public & some physicians; concerning palliative care (distinct from hospice):

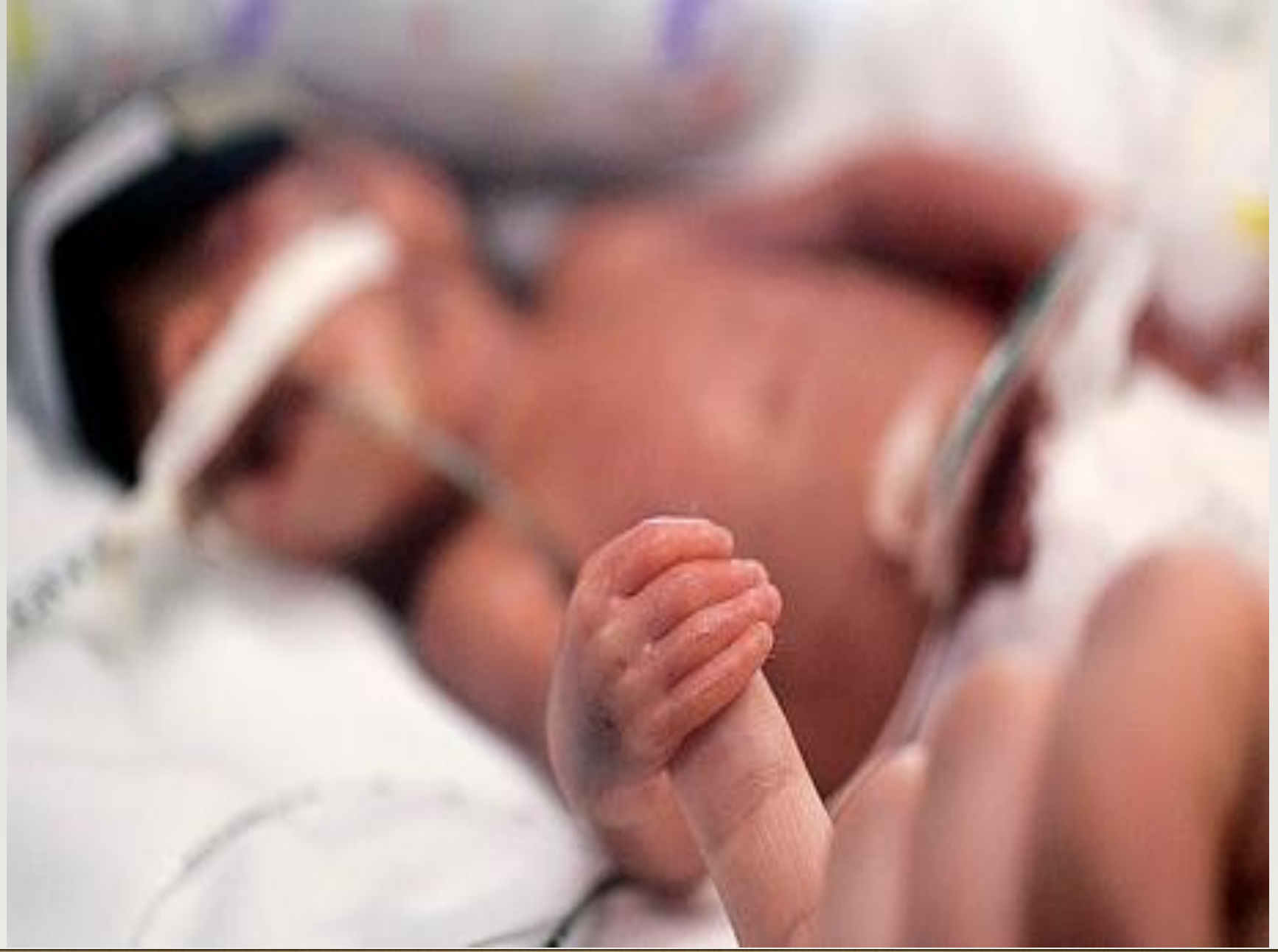
1. **If you accept palliative care, you must *stop treatment*.**
2. **Palliative care is the same as *hospice*.**
3. **Electing palliative care means you are *giving up*.**
4. **Palliative care *shortens life* expectancy.**
5. **Addressing pain & providing analgesia will hasten death.**
6. **Withholding treatment is less morally serious than withdrawing them.**

How should we counsel parents facing very early delivery?

Carefully, sensitively, empathically, and with compassion – in the words of parent, journalist & author Kelley Benham French.

Using a process of **empathic enquiry**, listening; demonstrating a willingness to consider their interests, their relationship (both fetal & anticipated neonatal), their goals/values and what matters most to them about their baby, in a culturally sensitive manner.

KB French Care of Extremely Small Premature Infants in the NICU - *Clin Perinatol* 2017; 44(2):275-282.



Juniper French, day of birth 23 weeks EGA, BW:574 grams

Technology and the "Fetal" Neonate

- ELGANs, ELBWs, VVLBWs…the periviable ones
- Matters of ***biology*** **meeting** ***technology***
  - Warmth, moisture, sterility & avoidance of infection, fluid/electrolyte/acid-base balance, respiration, nutrition, elimination, facilitating CNS development, growth.
  - Plastics
  - Ventilatory assist & O_2 delivery/monitoring devices
  - Steel->Teflon->silastic tubing & TPN
  - Drugs and their delivery systems
  - Monitoring, imaging, and laboratory techniques

Empathic Inquiry

Often when an infant is critically ill/with a life-limiting condition/or dying, the family feels trapped by the clinical situation. They're **drowning** in information and **want to talk.** The key is to **learn how to listen.**

One task, then, is to learn how to ask questions rather than just hide behind the information you're trained to provide. Too much information – especially if repeatedly stated – is like brow beating. Ask inviting questions that reveal a genuine interest in who they are & what matters, use empathic inquiry … build trust.

- **Associative reasoning**: Emotions guide thought by linking one idea to another in an "associative" way: in addition to thinking logically, we link ideas that have affective, sensory, and experiential similarities.
- **Emotional Attunement [Focus]**: Clinicians' emotions focus & hold their attention on what the patient is anxious about (e.g., body language, tone of voice, an evasive gaze) requiring more than simply words.
- **Facilitate Trust**: Engaging in empathy has therapeutic efficacy...it is linked to decreasing patient anxiety. It may allow patients to feel more comfortable, give fuller histories or insights to their values.
- **Allow Meaningfulness (It might even enrich your professional experience as a healer)**

Halpern J. What is clinical empathy? *J Gen Intern Med* 2003; 18(8):670-74.

Guidance from Professional Organizations

The goal of family counseling…is to provide:

1. "***objective information,*** in a
2. ***compassionate manner,*** to permit
3. ***shared decision making,*** and to
4. ***support the family.***"

Joint Workshop: Raju, et. al. Periviable birth: executive summary of a joint workshop of the Eunice Kennedy Shriver NICHD, Society for Maternal-Fetal Medicine, American Academy of Pediatrics and American College of Obstetricians and Gynecologists. *J Perinatol* 2014; 34:333-42.

Guidance from Professional Organizations

Effective counseling includes three components:

1. *"assessment of risks*
2. *communication of those risks,* and
3. *ongoing support."*

AAP: Cummings, J., for AAP Committee on Fetus and Newborn. Antenatal counseling regarding resuscitation and intensive care before 25 weeks of gestation. *Pediatrics* 2015;136(3):588-95.

Bad, Sad, and Life-Changing News

- **Deliver it?**
  - Pizza is delivered; so is the mail
- **Break it?**

  - News Feeds, TV/Internet all give “breaking news”
- **Give it?**
  - Here it is, its yours now…

- **Bear it?**
  - Lean into it, shoulder the burden with the patient/family
  - Requires empathy and presence

Not the Baby You Dreamed of…

- **Genetic problems**
  - Chromosomal (deletions, duplications, aneuploidy)
  - Structural (skeletal dysplasia, OI, body cleft, amniotic bands)
  - Metabolic conditions that may be complex; more…
- **Renal:** PCKD, MCDK, Potter's sequence, LUTO
- **CNS problems:** Hydranencephaly, complex NTD, SMA
- **Structural Heart Disease:** Single ventricle anatomy, mixed & complex CHD
- **GI:** Giant Omphalocele
- **Pulmonary:** Severe CDH; Lung hypoplasia; CPAM
- **Other:** conjoined twins, severe epidermolysis bullosa

One Case – One Conversation

- **Consider the location for the meeting; ensure all appropriate participants are present and briefed beforehand.**
- *'Tell me about your pregnancy. What have you been told?'*
- *'Would you like to talk about what might happen during labor and after your baby is born?'*
- **Break information into small chunks and focus on key messages.**
  - Check to see if the patient understands. *'Is this clear so far?'*
- **Address emotions with empathic responses**
  - *'I wish that these results were different…'*
  - *'I can't imagine how difficult this news must have been to hear'*
  - *'What is most important to you?'*
  - *'What worries you the most?'*
- **As we close**
  - *'What would you like to ask?'*
  - *'I'll follow up with a letter.'*

Sidgwick P, et al. *Arch Dis Child Educ Pract Ed* 2017;102:114–116.

Perinatal Palliative Care One Case (cont.)

"It was an appointment with a couple of palliative care pediatricians that changed everything. 'What would you like to happen?' *I knew exactly what I would like: I would like her to survive until the day I went into labor.*

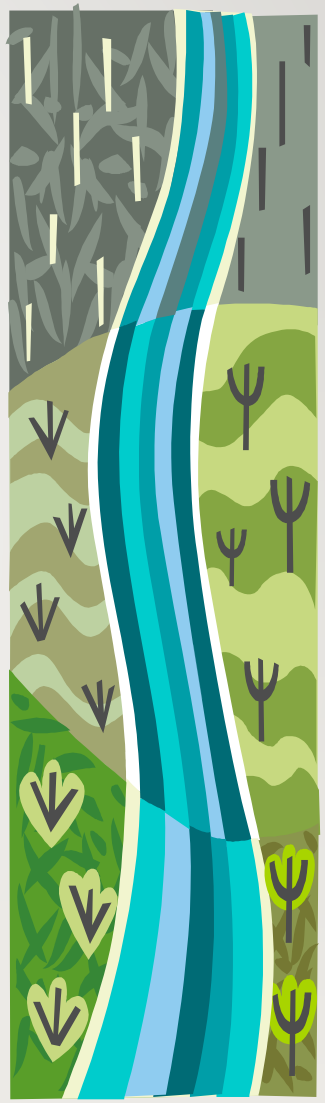
In the space of a couple of hours, they transformed what we were going through from something purely dreadful to something potentially meaningful. She could be a person, a person whom we might not have the chance to meet properly, but a someone nevertheless."

Ask → Listen → Ask

- Ask what the family knows and understands
- Ask what is important ***now*** to the family
  - And maybe what they fear most
- Speak frankly
- Encourage reflections
- Allow silence… and emotion

Perinatal Palliative Care

- *Prenatal Diagnosis*
  - *Discovery*
- *Questions & Research*
- *Coping & Choices*
  - *Anticipatory Grief*
  - *Support*
- *Birth*
- *Life & Love*
  - *Learning What is Needed*
  - *Letting Go*
- *Bereavement*



What Might a *Birth Plan* Look Like?

Clarify Maternal Goals

- **Site of delivery**
  - Community or tertiary
- **Fetal monitoring**
  - E-FHR, auscultation, none
- **Mode of delivery**
  - Burdens, benefits, values
- **Who will be in attendance**
  - Who matters
- **Maternal & neonatal medications**
  - Anesthesia & otherwise

Clarify Neonatal Goals

- **Specified components of resuscitation & care**
  - Intubate, CPAP, O_2?
  - Meds & lines?
- **Site of care of the baby**
  - L & D, Nursery, ICN, Home
- **Feeding plan**
  - Breast, Tube(s), cup, finger, no?
- **Special events & spiritual care**
  - Memories, mementoes, rituals
- **Contingency post-discharge plan**

Who might participate in planning?

Chaplains

Neonatologists

Child Life Specialist

Genetic Counselors

Pediatricians

EMS providers

Perinatologists

PARENTS

Radiologists

Social Workers

Sonographers

YOU

Ethics Consultants

Obstetricians

NICU staff

Siblings

Lactation Consultant

Grandparents

Midwives

Family Doctors

Geneticists

L & D and postpartum staff

Physical / Occupational Therapists

The model of palliative care in the perinatal setting: a review of the literature

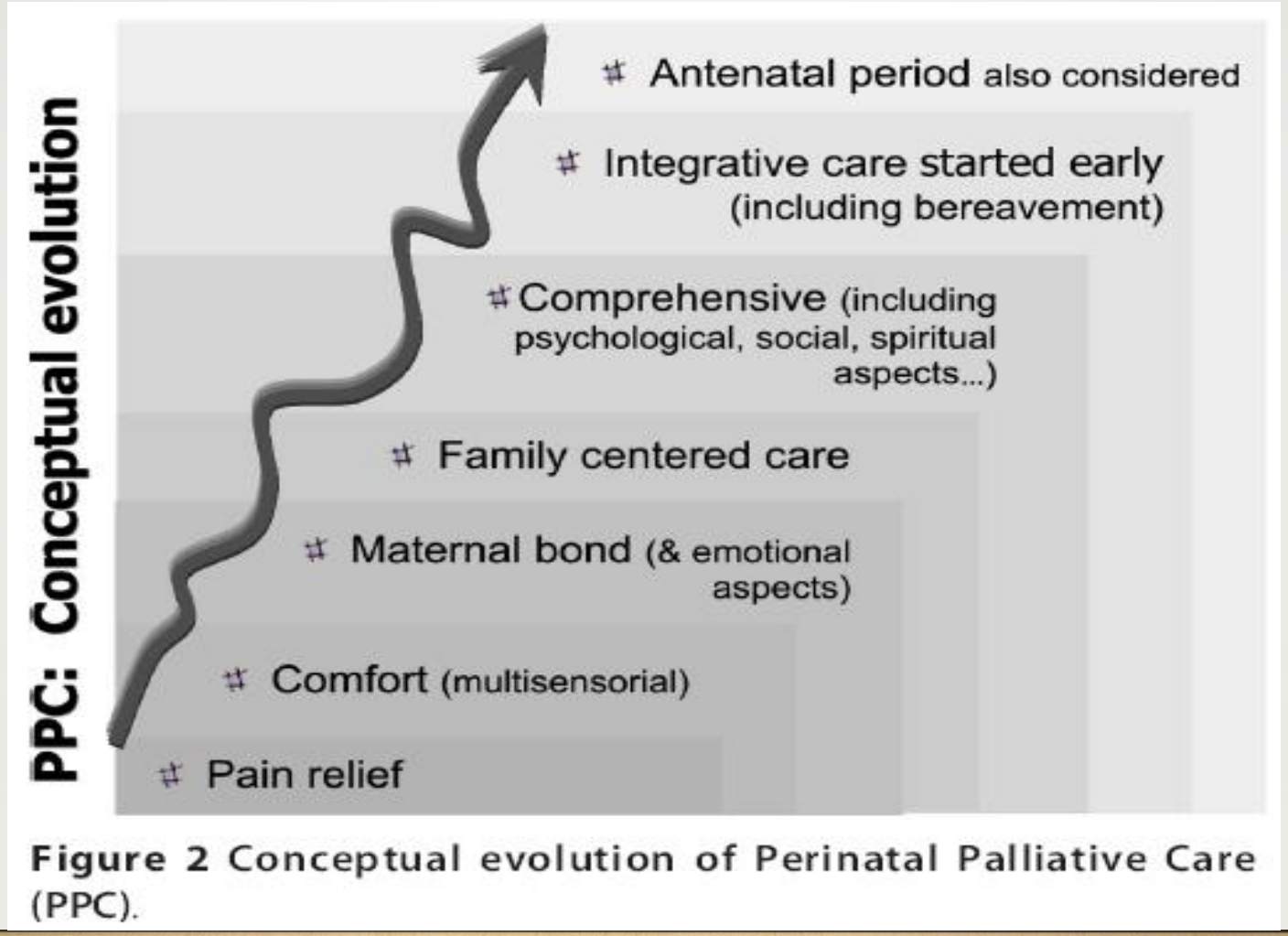
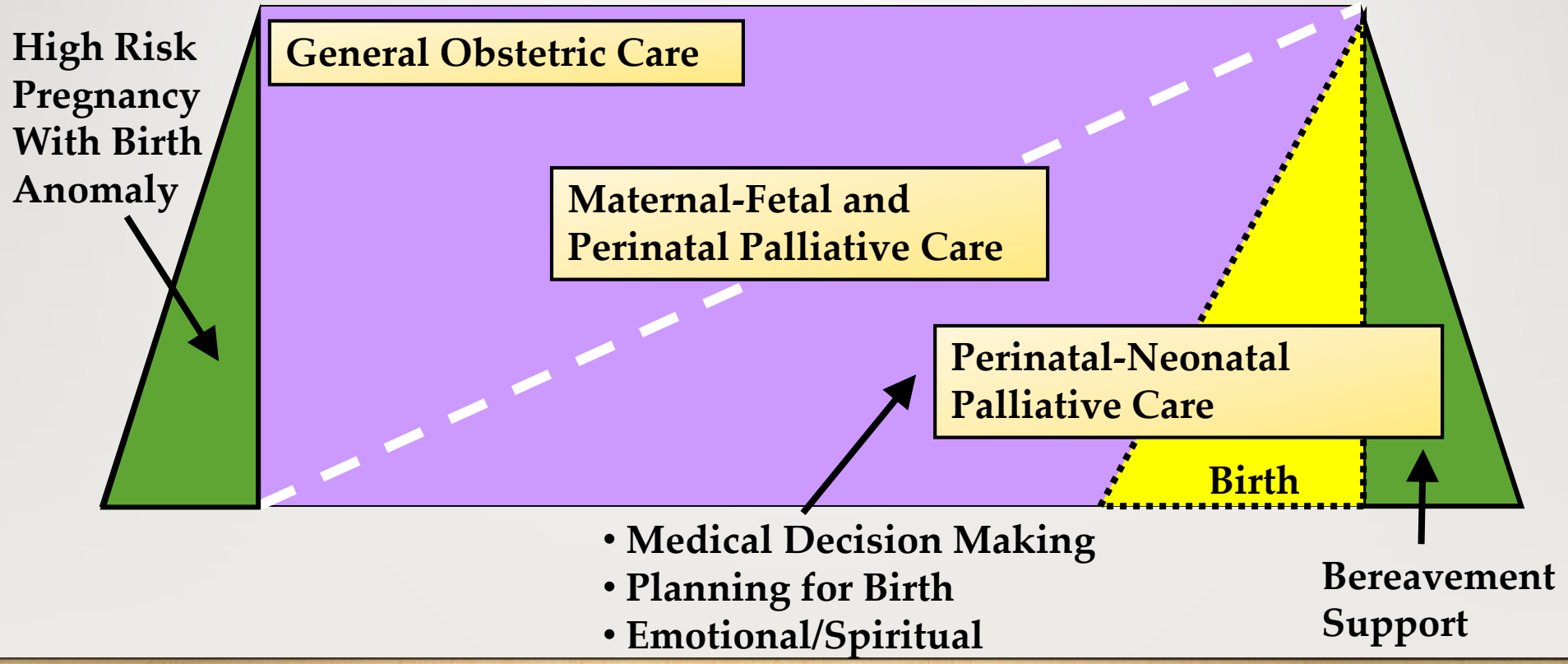


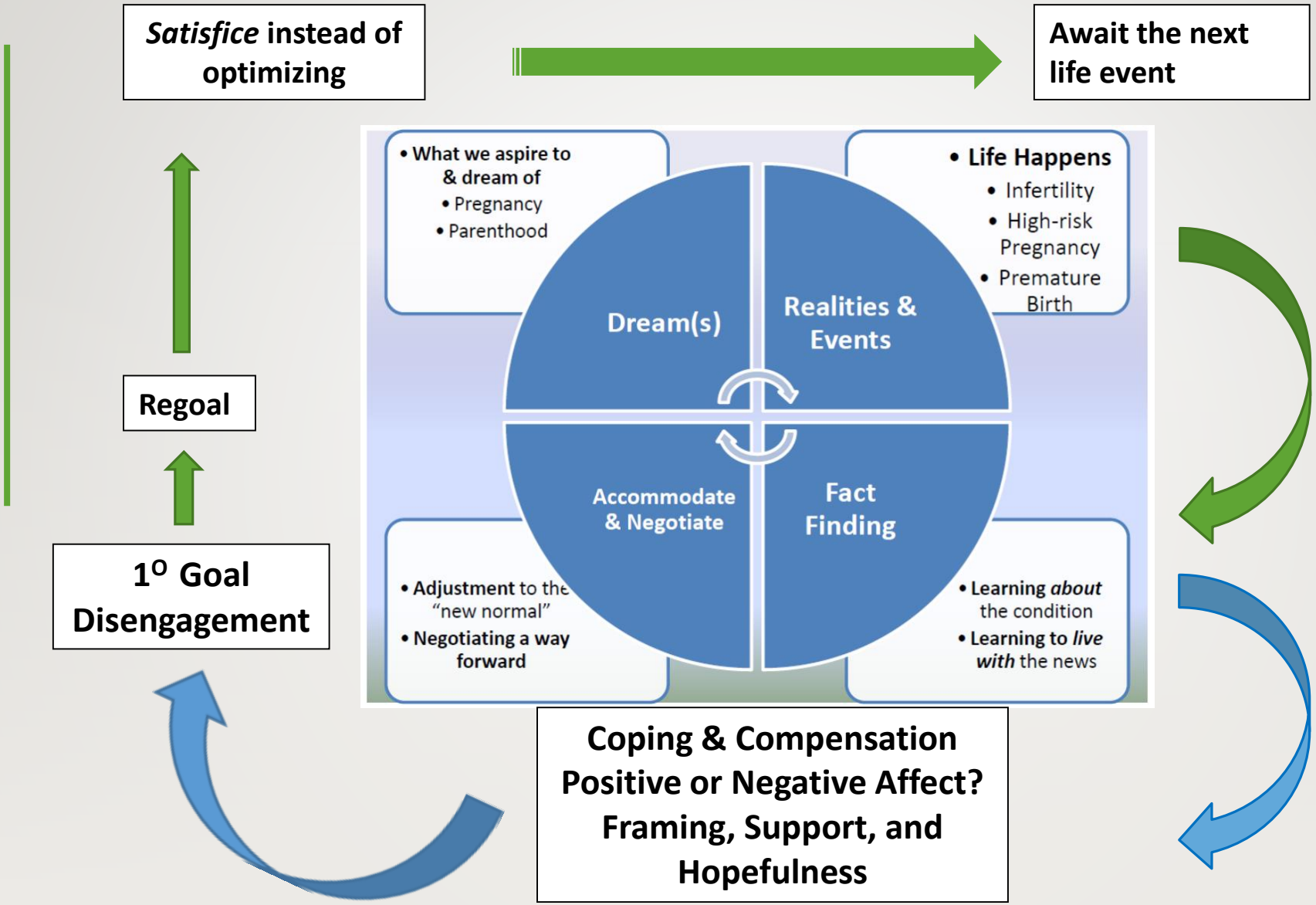
Figure 2 Conceptual evolution of Perinatal Palliative Care (PPC).

Albert Balaguer et al. (Spain) *BMC Pediatrics* 2012, 12:25

A Continuum of Care

Perinatal-Neonatal Palliative Care through the Trajectory of Pregnancy, Birth and Beyond





Journal of Perinatology (2019) 39:1692–1693. https://doi.org/10.1038/s41372-019-0526-3

Focusing on relationships, not information, respects autonomy

Gaucher & Payot, *Acta Paediatr* 2017; 106(1): 14-20

- **Clinicians need to explore individual parents' lived experiences and engage in trusting empowering relationships.**
- **Clinicians can enhance parents' relational autonomy by becoming advocates for them & partnering with them.**
- ***Relational* rather than *Rational Individualistic* Autonomy**

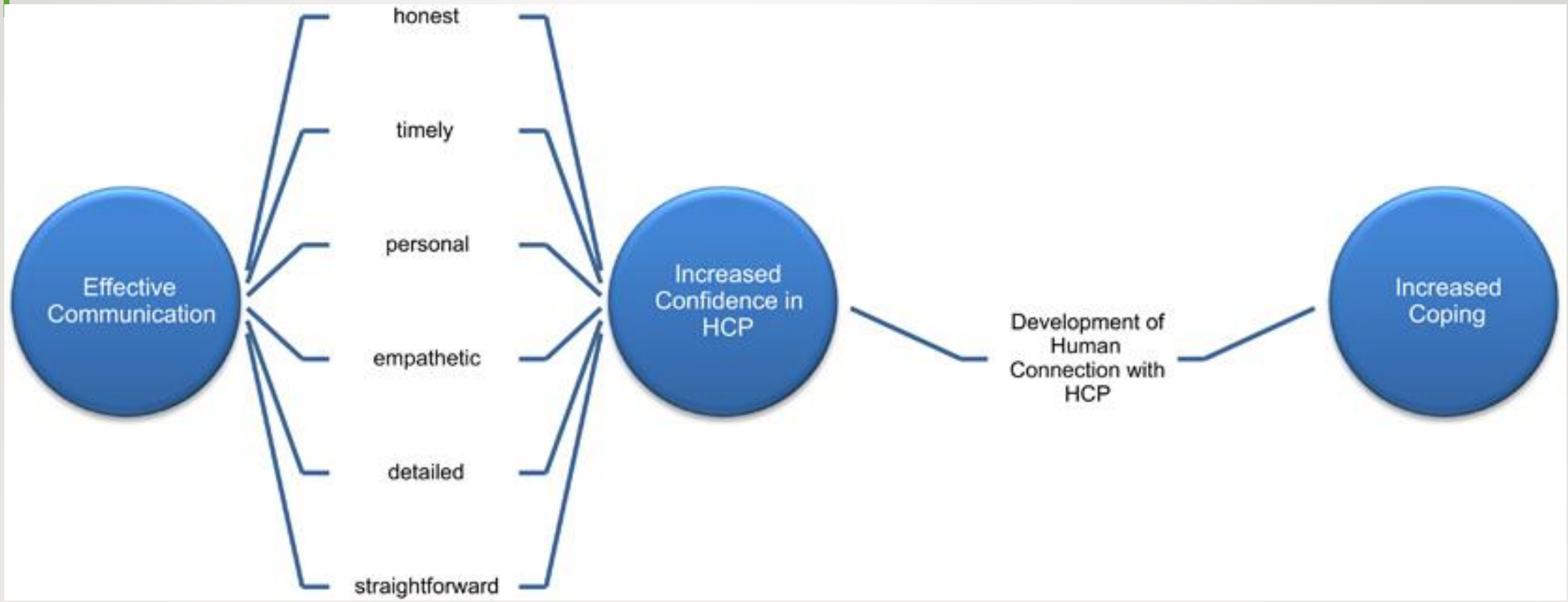
Self-determination

- relational moral agent
- reason and emotion
- facilitates information-delivery

Situational awareness

- each person's lived experience
- power imbalance
- contextual issues

Relationship between Health Care Professional communication, parental confidence & coping



Health-care provider communication with expectant parents during a prenatal diagnosis: an integrative review. AL Kratovil & WA Julion. *J Perinatol* (2017) 37, 2–12.

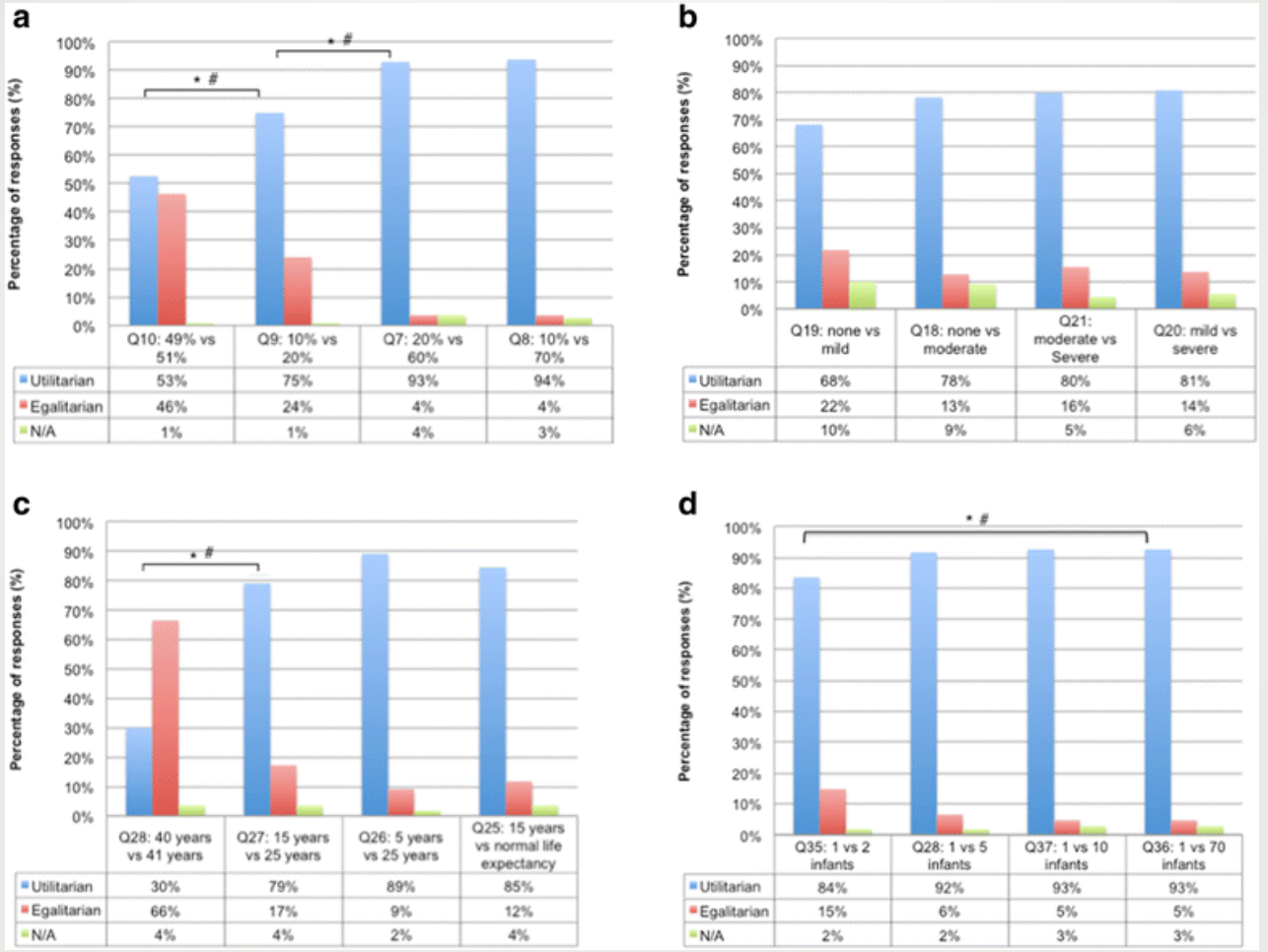
The ICU Lifeboat: a survey of lay attitudes to rationing dilemmas in the NICU

Survival

Disability

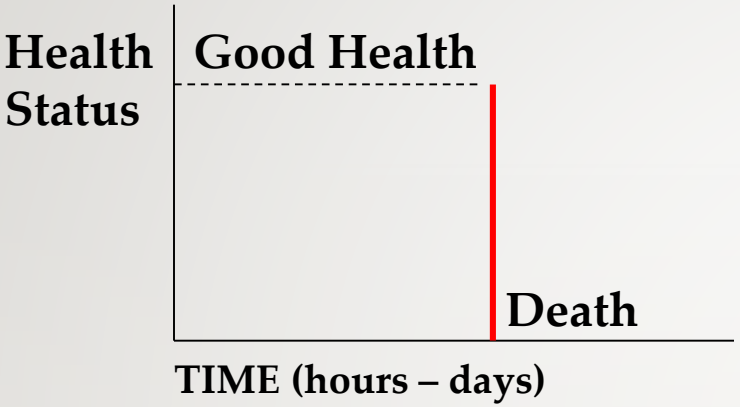
Lifespan

$$ of Treatment Baby or more

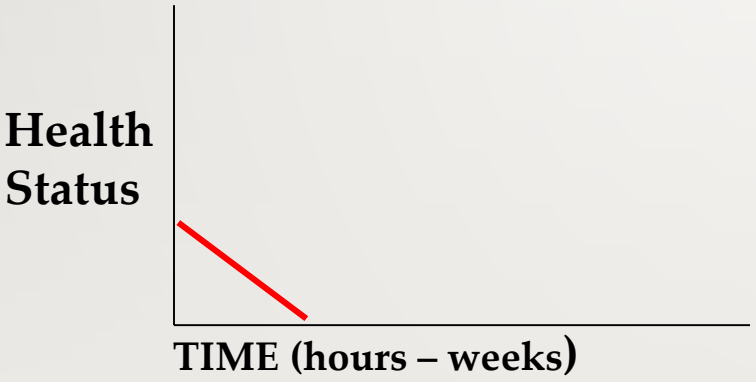


Arora et al. *BMC Medical Ethics* (2016) 17:69

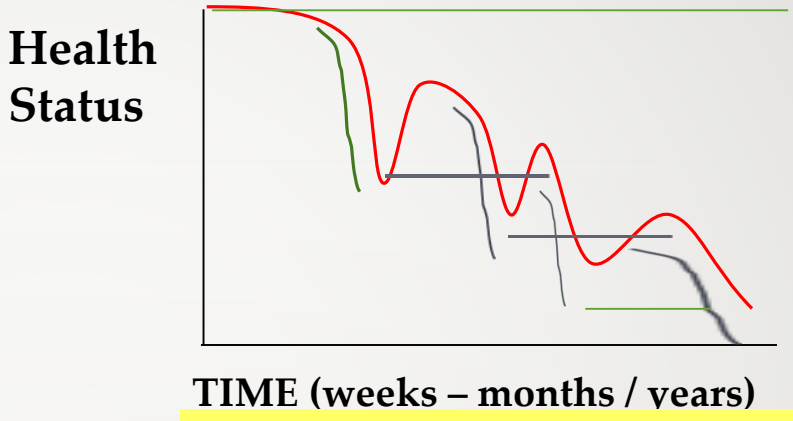
Neonatal-Pediatric Death Trajectories



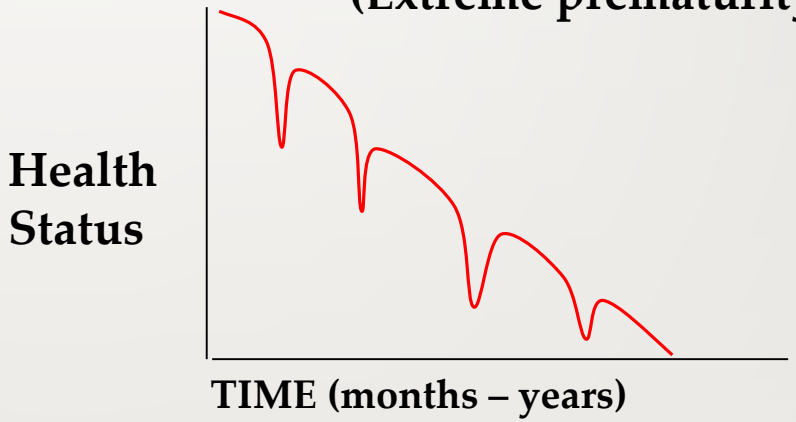
Sudden / Unexpected



Trisomy 13/18



Potentially curable, but with declines
(Extreme prematurity)



Progressive (neuromuscular)

Postnatal Genetic Diagnoses

- Were prenatal diagnostics pursued?
- Was there antepartum counsel/care.
- Newborn resuscitation, intensive care, diagnostic confirmation, next steps…
- Coordinated in-hospital care
- Palliative Care consultation or provision; availability of f/u care?
- Coordinated care thereafter

What Matters in the NICU?

- **When possible, clarity of a Diagnosis**
  - Gives family comfort
  - Allows for prognostication & staff to work together
  - Determines measures of support & frame questions of care needs
- **Frequent Care Discussions**
  - Respiratory support (minimal, non-invasive, invasive), surgeries?
  - Clinical assessments and Value-based assessments
- **Consultants**…what is possible as an inpatient may not be possible at home
- **Expected early death?**
- **Expected discharge home?**

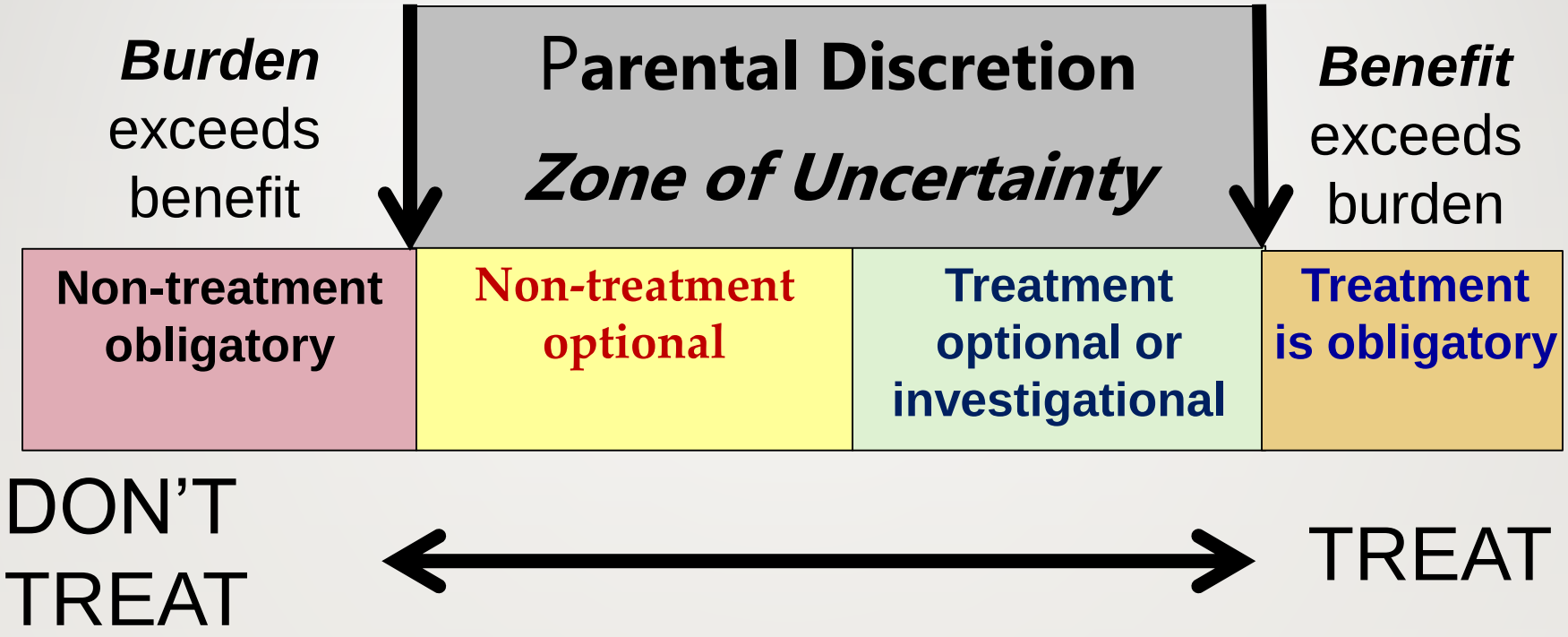
Are There Questions for an Ethicist?

- What is ***beneficial***?
- Is the baby ***suffering***?
- Do the Staff have ***moral angst or distress***?
- Do the parents insist on care that is not helpful?
- How might we find an acceptable way forward, that considers family values and culture but does not harm the baby by prolonged, ineffective technology?

Why families may insist on aggressive care

- A child's death is **untimely – indeed unnatural.**
- **It's a parent's duty to protect children from harm.**
- It may be that there has been **inconsistent or conflicting messaging around diagnoses, prognoses, and realistic possibilities.**
- **Communication may not really have been accomplished.**
- Medical **facts do not equate to truths.**
- **Clinicians aren't considered to have a valid place in addressing death – it's up to God.**
- **Miracle language** may be invoked as a means of demonstrating a religious or spiritual claim.
- **Genuine stress & poor or overwhelmed coping mechanisms** may lead to demands.
- **There is secondary gain** in keeping the child alive.
- **Families [and clinicians] retain an inherent belief in science/technology to be able to fix/cure anything.**

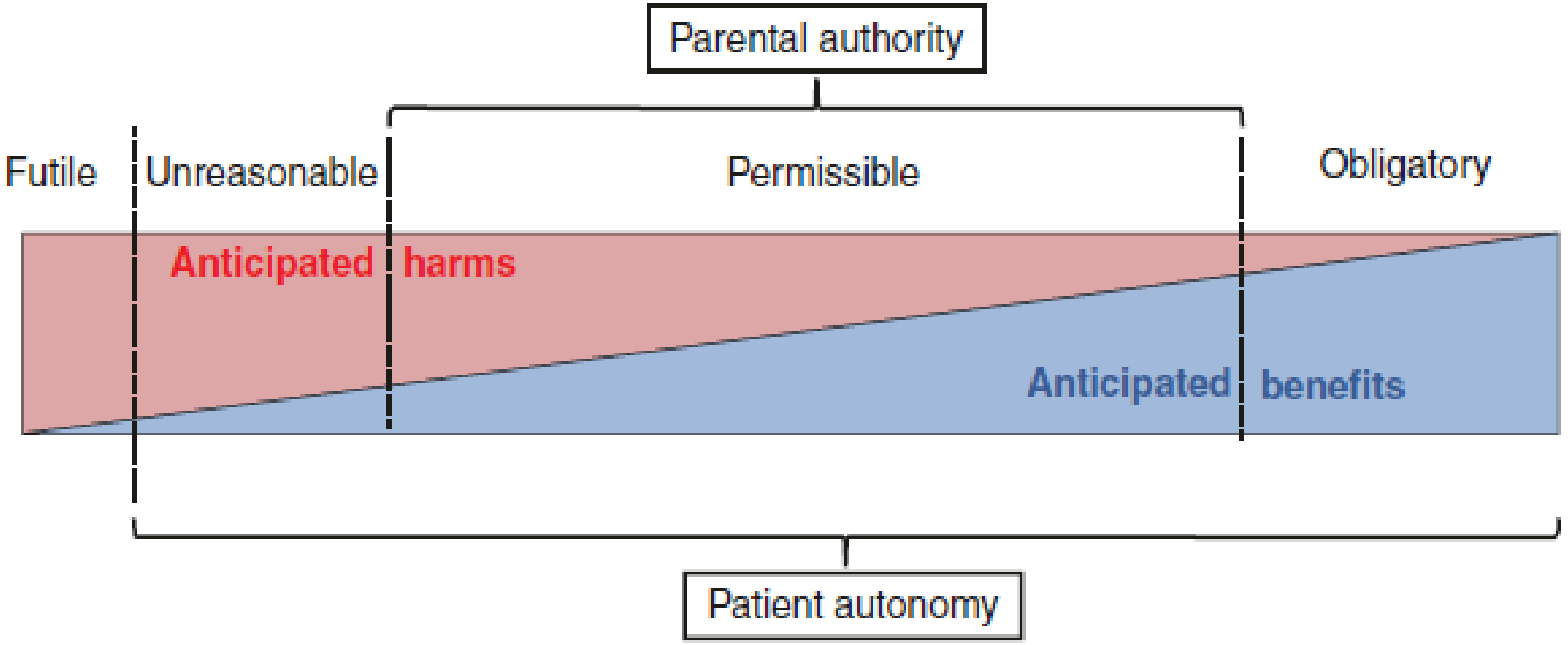
Sharing decision making with parents: allowing comfort care *or* resuscitation at 22 and 23 weeks; resuscitation at 24 weeks and over. The effective gray zone has shrunk.



Where are you on this line?

Brian Carter

Limits of Parental Authority and Patient Autonomy



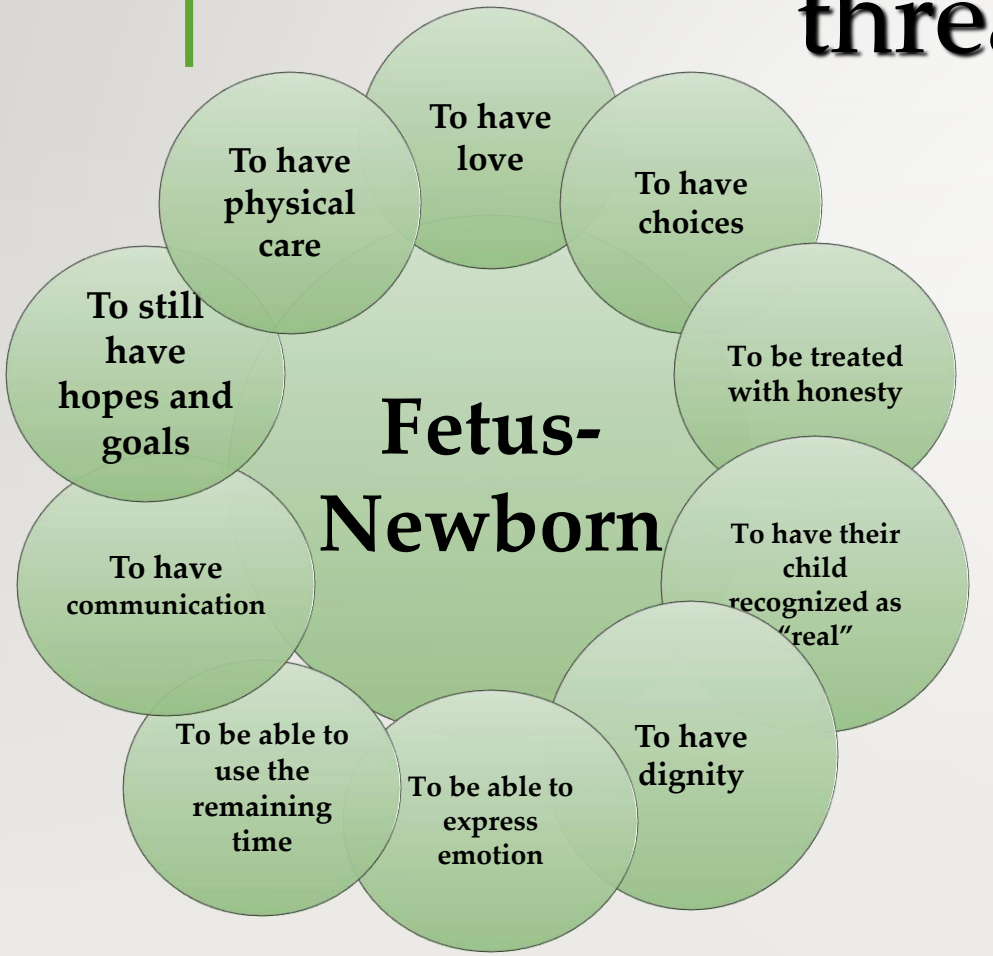
From Wax, D'Angio & Chiafery (2020). *Perinatal Ethics*
In Denney-Koelsch & Cote' Arsenault Perinatal Palliative Care. Springer Nature Switzerland AG.

Palliative Care in the NICU
Is It Available?

- ***Who*** *introduces the notion, and when?*
  - *Nurses, doctors, the NICU care team or even parents*
- ***What*** *will neonatal-perinatal palliative care add?*
  - ***Comfort*** *&* ***symptom management*** for the baby
  - Added support (psycho-social-spiritual) for the parents/family
- ***Which babies*** *might appropriately be considered for it?*
  - Babies with life-threatening/limiting conditions for whom an early death is anticipated & those who have outstripped the benefits of technological support
- ***When there isn't a palliative care consultant*** *can I simply practice good intensive care?*

  YES!

Needs of parents of a baby with a life-threatening illness



Adapted from A. Goldman

Care of the Dying Child,

1994

Make Perinatal Loss Real for Siblings: Parental Advise

Avelin, et al. *J Perinatal Education* 2012 Spring;21(2):90-98

Subject	**Mothers** (*n* = 350)	**Fathers** (*n* = 61)
Seeing their stillborn baby	*n* = 328 (93.7%)	*n* = 60 (98.4%)
Holding their stillborn baby	*n* = 266 (76.0%)	*n* = 52 (85.2%)
Collecting ***mementoes*** of their stillborn baby	*n* = 295 (84.3%)	*n* = 55 (90.7%)
Having ***photographs*** of their stillborn baby	*n* = 310 (88.6%)	*n* = 58 (95.1%)
Took their stillborn baby ***home*** before the funeral	*n* = 8 (2.3%)	*n* = 2 (3.3%)
Had a ***funera***l for their stillborn baby	*n* = 305 (87.1%)	*n* = 59 (96.7%)

Parental Experiences of Seeing, Holding, Taking the Stillborn Baby Home, Collecting Mementoes of the Stillborn Baby, and Arranging the Baby's Funeral in Number (*n*) and Percentage (%)

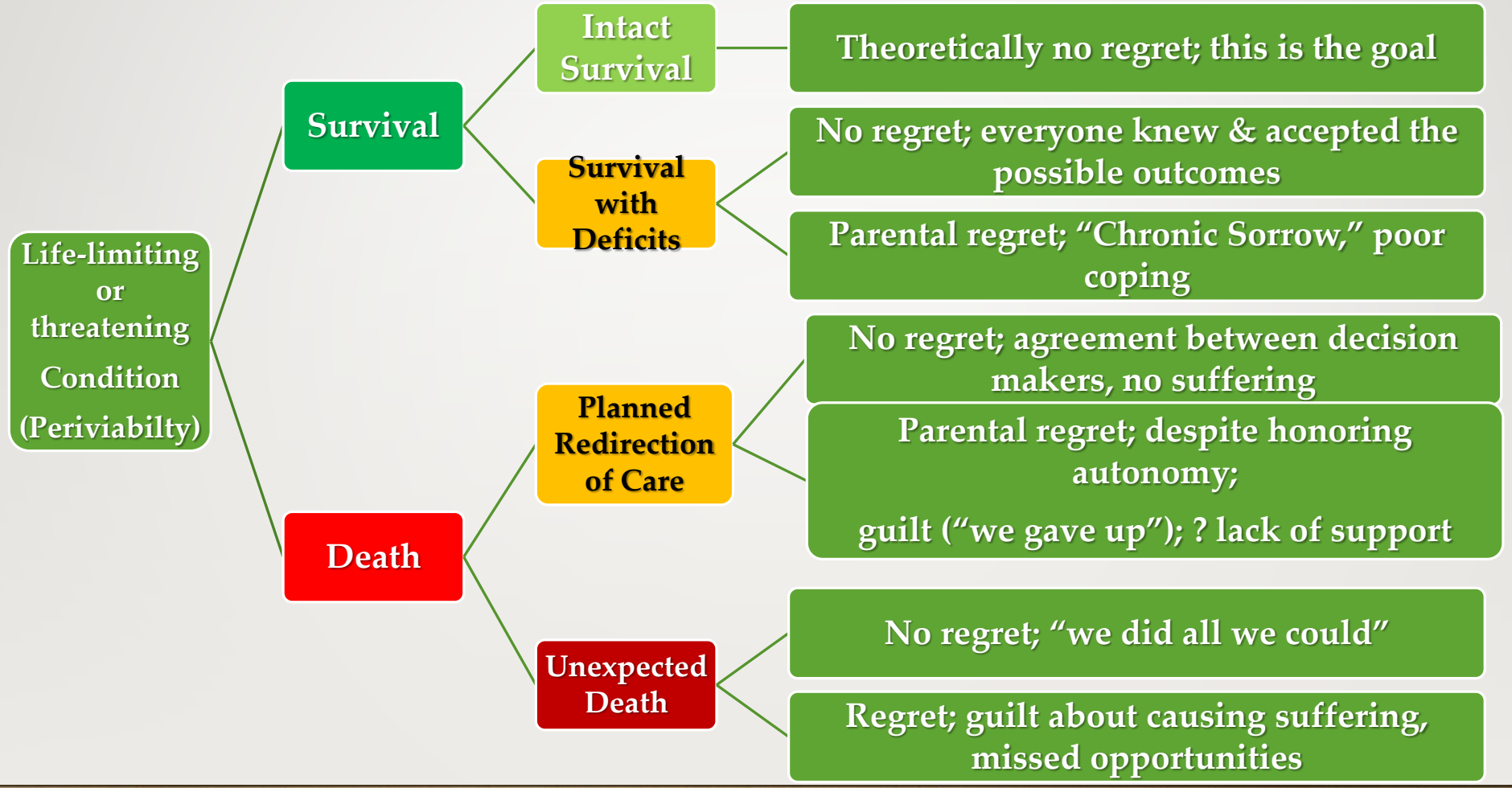
Vicky Forman this lovely life

"I learned about grief during this time… Of what I had lost and would never have again, of what I had once allowed myself to want, the things I used to love."

Decisions, Outcomes, & Decisional Regret

Values-based shared decision-making in the antenatal period

Kukora & Boss, *Sem Perinatol* 2018



Palliative Care & the Liminal

From the prenatal period onward, the fetus – newborn – infant & child who has a complex chronic medical condition [& their families] occupy a *liminal* space

- Many of us tend to disease models rather than relational models – it's expedient!
- But common practices, efficiency & expediency do not lend themselves to dealing with the transitional or unbounded nature of patients and families in this space/time
  - Not quite dying, not really living
  - Wondering what is real, what comes next

Narrative approaches are beneficial, and likely necessary

- For the patient/family to live, reflect upon and tell
- For PPC & ethics consultants to listen to, hear, and incorporate into ethical solutions for these special cases of children who are in transition

Narrative Neonatology. Fleishman, et al. *J Perinatology* 2022