Her Smile Is Enough for Me: Critical Care Pediatric Chaplaincy

Jim Manzardo, STB, BCC and Glenda Spearman, MDiv, BCC
Objectives

• Understand the complex neonatal and pediatric intensive care world in which caregivers are forced to confront the harsh reality of their child’s neurological devastation and/or poor prognosis.

• Understand the existential and spiritual transformation parents experience after choosing life-prolonging interventions and the chaplain accompaniment role.

• Appreciate the chaplain role in supporting ICU staff who care for these children and families and who experience their own ethical and moral dilemmas and distress.
The Pediatric Intensive Care Unit (ICU) World*

A child’s emergent admission to the pediatric intensive care units causes fear and feelings of helplessness in parents who only hours earlier had been in control of their lives...the ICU is a place where death can and does occur.

From the parents’ perspective, intensive care units are busy and intimidating places, dominated by sick children, worried staff and family members, advanced medical technology, bright lights and shrill monitors...

Parents are introduced to many unfamiliar staff members whom they perceive as holding the child’s fate in their hands. The technical language that staff members use may be confusing, and parents often search the faces of physicians and nurses for clues about how their child is really doing. Although the ICU may be a traumatic environment, it also offers hope to families, sometimes the last hope.

Parents’ Experiences of the ICU*

- There was a baby in the cot and it was mine but I couldn’t feel anything. I was just standing there watching.
- They told me a thousand times but nothing stuck, everything was just chaos.
- All the beeping and the flashing lights distressed me greatly. It was hard to concentrate on my child.
- It felt so unreal; there was my child in the middle of all this.
- I just remember that the surgeon said ‘not live’, but he never said the word ‘die’.

The existential and spiritual complexity: The human person

• What does it mean to be human, a person?
• Can circumstances change that meaning?
• What does it mean to be a parent?
• How does that meaning change with a child with medically complex needs?
• Are there limits to medical interventions? Who decides the limits?
• How does a parent decide what is best for their critically ill child?
The existential and relational complexity: The Various Players

- The child
- The parents
- The family
- The medical team. And each member of the team has a unique perspective. The medical team yes sees the unique child but also sees her as a diagnosis, as falling into a group of those others who have had that diagnosis.
- The medical interventions: medicines and technology.
PHOTOS

NICU

PICU
Welcome to Holland

“But I don’t know anything about Holland!” you say. “I don’t want to stay!”

Emily Perl Kingsley
NICU

- A whole breadth of patient conditions.
- A whole breadth of parental situations: age, education, socioeconomics, religion, culture, language, gender, residency status
- A whole breadth of family situations.
- A whole breadth of medical and non-medical clinicians.
- A whole breadth of medical interventions.
WOW! How is a parent to decide?

How overwhelming, everyday, to be confronted with all these people with whom a parent must interact, all these interventions to which a parent is being asked to give consent and all these medicines with multiple side-effects about which they know so little?

And, then, there is the Internet...
PICU

• A whole breadth of patient conditions.
• A whole breadth of parental situations: age, education, socioeconomics, religion, culture, language, gender, residency status
• A whole breadth of family situations.
• A whole breadth of medical and non-medical clinicians.
• A whole breadth of medical interventions.
The Parent’s Experience

• Each parent arrives with their own framework and different degrees of awareness.

• Each parent arrives with different levels of internal and external resources for coping and decision-making.

• Parental guilt, shame.

• Variations in parental involvement.

• The “roller coaster ride”.

• Varieties of stressors.
Parents-Staff Relationships

- The cultural, educational, experiential differences
- Trust vs Mistrust
- Religious and Spiritual influences
- Role reversal of critical medical decisions
Questions and Responses
Victoria: A NICU Case
Princess: A PICU Case
Common Themes*

- From shock, disbelief and grief to acknowledging a disrupted world and living and reconciling with great uncertainty
  
  *Toward a Spirituality of Ambiguity*

- From despair to hope, ever-shifting, and to rethinking priorities, reframing beliefs, making the most of their lives and restoring significant relationships

  *Toward a Spirituality of Hope*

- From being stuck to moving forward by discovering a “new normal” and attaching new meaning

  *Toward a Spirituality of Gratitude*

---

Questions and Responses
Chaplains and Support of ICU Staff

• Particular dilemmas, questions, distress arising from ICU staff
• Ways staff attempt to make meaning amidst these situations
• When their meaning-making hits the limits and leads them to moral and/or spiritual distress
• How chaplains companion and support ICU staff
• How chaplains maintain professional distance in order to benefit staff
• How pediatric chaplains attend to their own needs in order to do this work
Questions and Comments
Bibliography


• Brelsford, GM & Doheny, KK. Religious and Spiritual Journeys: Brief Reflections from Mothers and Fathers in a Neonatal Intensive Care Unit. Pastoral Psychol (2016) 65:79–87


• Gribben, JL, BS et al. A Cross-Sectional Analysis of Compassion Fatigue, Burnout, and Compassion Satisfaction in Pediatric Critical Care Physicians in the United States. Pediatric Critical Care Medicine. 2018 Vol XX.
