SHELTER IN THE STORM:

THE ROLE OF PALLIATIVE CARE & HOSPICE IN THE CARE OF AN INFANT WITH PROGRESSIVE NEUROLOGICAL DECLINE

Case Study Presented by:
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- As we tell you the story of beautiful infant "A.J." think about:
  - How this case could have been handled differently to improve outcomes?
  - What alternatives to the medical/surgical management of this infant and others like her were there?
  - What could have been done to coordinate care better?
  - How could we have made decision making easier for the family?
  - What would have improved communication and continuity of care?

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- The story of "A.J."
- A.J. suffered a prenatal hypoxic injury of unknown etiology and then developed seizures on day 1 of life.
  - 2 month stay in the NICU at an outside facility.
- Her PCP referred the family to Palliative Medicine at 3 months of age…after discharge.
  - Apnea at home
  - Suspected life limiting trajectory of hypoxic brain injury

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- We met A.J. and her parents in our PICU after tracheotomy and g-tube placement…

- Her care was complex from the beginning and impacted by:
  - Multiple disciplines
    - Discuss the impact of ancillary services such as Social Work, Child Life, other
  - Several subspecialty care teams
  - Nursing staff and management

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- When would have been the best time to refer A.J. to Palliative Medicine?
  - A. Pre-natal
  - B. NICU
  - C. Trach Clinic appointment
  - D. PICU/acute care service

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- Requests from all services and nursing to help with advanced care planning beginning with the PICU…
- Advanced care planning process for A.J. was impacted by:
  - Difficult family dynamics
  - CPS involvement
  - Staff and provider assumptions, biases
  - Communication
- Decision making in the context of such difficult family dynamics.

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- Advanced care planning is most improved by
  - A. Early referral to Palliative Medicine.
  - B. Gentle, supportive and understanding efforts by nursing and subspecialists to change code status each admission.
  - C. Multiple care conferences.
  - D. Coordinated care that helps families assess intervention by looking at the “big picture”.

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- A.J. was referred to hospice care at 8 months of age after multiple extended re-admissions…

- There were several confounding factors in her hospice referral:
  - Barriers to early hospice referral with this family.
  - Identification of follow up difficulties
    - Subspecialty outpatient care
    - Hospice care planning and treatment
  - Difficulties in symptom management and end of life care.

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- What is the biggest barrier to hospice care in this case and many other pediatric patients?
  - A. Delayed acceptance of a terminal condition by her parents.
  - B. Poor socioeconomic status.
  - C. Cultural and religious beliefs that delay admission to hospice care.
  - D. Rural, difficult to reach location of the home.

- Reference: Linton, J. M. & Feudtner, C. (2008). What accounts for differences or disparities in pediatric palliative and end of life care? A systematic review focusing on possible multilevel mechanisms. *Pediatrics 2008;122;574.* DOI: 10.1542/peds.2007-3042

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- In conclusion –
- The story of A.J. is not unlike that of children you will meet in your own practice.
  - What "pearls" have we all learned from her life story?
  - Last thoughts on how the short life of A.J. will impact your team going forward?
    - Your practice as individual?

REFERENCES:
See handout

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- Thank you for your insights and participation!

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