Lessons Learned:
Developing and Implementing
a Perinatal Hospice Program
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Objectives

• Describe an overview of services at TEH and CCC
• Discuss the origins and evolution of the TEH Perinatal Program
• Compare and contrast the components of the Perinatal consent and admission protocols with the adult population
• Describe the development of a training program and Standards of Practice in the community
• Identify key do’s and don’ts in starting a Perinatal Program
Overview:
TEH Children's Services

- Our beginnings
- Our journey
- Where we are now
- Our vision
Setting the Stage

- Organization that historically had a very elderly aged pt. population and rarely had peds admissions (>85)
- Changing demographics to younger adults (<40)
- ADC and defined service area

- Based on community need, TEH started a pediatric program that serviced both Pediatrics and Perinatal
- Lack of exposure to and understanding of scope of perinatal hospice care by staff
- Ill-defined program at beginning
- Became more defined after an outlier complicated first case
Where Do We Start?

• No one “correct” way to start a program!
• Traditional beginnings:
  • Well established hospice program
  • Begins serving newborns and infants
  • Accepts perinatal cases
  • Responds to the program’s growing need for bereavement support
How We Started

• “The end is where we start from.”

  …T.S. Eliot

Spring 2011: In response to an expressed need—
  – Partnership with local non-profit, Empty Cradle
  – Collaboration expanded from one co-facilitated group to two groups in two communities
How We Started

- Solidified support groups led to perinatal/neonatal bereavement referrals from local hospitals

- Built and fostered relationships with referring social workers, nurses, and physicians

- 2012—Two parallel initiatives at TEH began to converge
How We Started

– As Pediatric Program launched, unmet need for Perinatal Program identified—other local hospice would not offer this service

– Preparation for spectrum of perinatal cases—induction, stillbirth, neonatal death

– First perinatal case accepted!
How We Started

– Perinatal Hospice Training as part of the Pediatric Palliative Care Series

– ELNEC

– In the field

– At the hospital /Birthing Center/Home
Care Continuum - Before, During and After Birth

- Primarily anticipatory guidance and emotional support
- Social worker or Counselor plays primary role
- Nurse plays a secondary role
- **Birthing Plan** - cornerstone of care support as main care planning tool
Care Continuum - Before, During and After Birth

- Support During pregnancy
- Support at Delivery if necessary
- Collaboration with Hospital Team
- Possible Transition to Pediatric Team
Birthing Plan

A tool to assist in beginning difficult discussions
- Diagnosis
- Who do you want at the birth?
- Care During Labor
- Care After Delivery
- Newborn Care
- Plan for Home care
- Plan for final arrangements

- Not legal or binding
- Copies given to MD, family, hospice, and hospital
Lessons Learned

• Unique starting point through bereavement program first led to interface with perinatal loss group and perinatal hospice care
• Asked to do home deliveries with non-nurse certified midwives
• Balance of best staffing model vs optimal staffing more similar to hospice
• Utilization of resources: who is the “director” of care with perinatal care
• Overlapping or conflicting scope of practice between social work and licensed counselor (or bereavement staff)
Lessons Learned

• Referrals for terminations > not a fit. Need to clarify scope of service.
• In effort to be inclusive, too many staff became involved for various reasons…Vague criteria to participate and poor engagement when needed…Evolved to a smaller core team.
• Avoid participation as a “spectator sport.”
• Start small, get trained, and then add people.
• Home Births
Organizational Realities

• Conceptual Framework of Perinatal Program is foreign:
  – Who is the patient?
  – How can hospice help?
  – Who pays for it?
Key Points

- Emphasize non-medical program to avoid confusion and conflict of coverage when a hospice home based program
- Communicate with Senior Leaders with facts
- Non-involved staff need to be informed
- Make the case ahead of implementation, have infrastructure set or planned before taking cases…
- Gaps will appear in retrospect
Key Points

• Be proactive in anticipating emotional response when finally faced with a child or baby dying...“facing our fears”
• Program ignites a lot of emotion and charge at all levels of agency
• Interest does not equal qualified to participate
Marketing and Education: Not like adult

- Sensitivity
- Education
NEED A HUG?
Comfort Cubs: The Comfort Cub Helps Takotsubo Syndrome

- Marcella and baby George's story
- www.thecomfortcub.com
First Steps

- Inventory your community—need? resources?
- Training on perinatal palliative care: ELNEC training module on perinatal is very relevant.
- Materials/Supplies needed
- Keepsake materials
To proceed or not proceed?

- Be Innovative!
- Create to the need of the community!
- Align with organizational goals—A MUST!
- PLAN: A well thought out program will more likely succeed.
- Do not let small obstacles get in your way!
“It’s not that I’m smart, it’s just that I stick with problems longer.” Albert Einstein

“Never, never, never, never, never, never, never, never quit!” Winston Churchill

“If I would have asked people what they wanted, they would have said faster horses.” Henry Ford
Resources for Help

- [www.perinatalhospice.org](http://www.perinatalhospice.org)
- NHPCO/PEDS. CHIPPS E-Journal
- Gunderson Lutheran: perinatal loss resources
- Now I Lay Me Down to Sleep (NILMDTS.org)
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