# Perinatal Hospice:
## What it means to do no harm-Medical ethics and anomalous pregnancies

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# PERINATAL HOSPICE: COMPREHENSIVE CARE MODEL FOR FAMILIES WITH ADVERSE PRENATAL DIAGNOSES

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# OUTLINE

I. Introduction

II. Hospice concepts

III. Definition

IV. How done

V. Results

VI. Challenges

# OBJECTIVES

- Understand pressing needs for in-utero infants with life limiting diagnosis & families
- Become familiar with the general hospice concepts
- Understand mechanisms for implementation of “perinatal hospice”
- Be empowered to create a “perinatal hospice” within own health care system

# INTRODUCTION: SCOPE OF THE PROBLEM

- Increasing ability to diagnose fetal anomalies before birth
- Birth Defects are the leading cause of neonatal death in the United States [1]
- Incidence of lethal anomalies at birth is 0.2-0.3%
- Lethal anomalies in the United States:
- 6-10,000/year [2]

[1]March of Dimes. (2001). *Maternal, infant, and child health in the United States*. White Plains, NY: March of Dimes Perinatal Data Center.

[2]Centers for Disease Control. (1998). *Trends in Infant Mortality Attributable to Birth Defects-United States, 1980-1995*. Atlanta, GA: CDC.

# PREVIOUS OPTIONS

## Traditional Counseling: Termination

- Well-intentioned desire to spare moms & families distressing experiences: “get it over with”
- Obstetric providers’ desire to “do something” and their discomfort with bereaved patients
- Well-intentioned desire to avoid maternal complications of pregnancy and childbirth`
- Fear of increased maternal mortality

# GRIEF AFTER TERMINATION INTENSE AS SPONTANEOUS LOSS

- Case control of group of 23 women with termination for anomalies[3]
- Grief responses similar at 2 months
- 4/23 (17%) with major depression
- 5/23 (22%) sought psychiatric counseling

[3]Zeanah CH, Dailey JV, Rosenblatt MJ, Saller DN. Do women grieve after terminating pregnancies because of fetal anomalies? A controlled investigation. Obstet Gynecol 1993;82(2):270-275

# GRIEF WITH FIRST TRIMESTER SPONTANEOUS LOSS EQUAL TO THOSE WITH LIVE BIRTH

- Recent study in 2009 of 147 women in Netherlands with abortion of pregnancy for anomalies[4]
- Reviewed psychological outcomes at 4,8, & 16 months
- At 4 months 46% women revealed pathological levels of posttraumatic stress symptoms
- At 16 months 21% still have symptoms

[4]Korenromp MJ, Page-Christiaens gCML, Van den Bout J, Mulder EJH, Visser GHA. Adjustment to termination of pregnancy for fetal anomaly: a longitudinal study in women in women at 4, 8, & 16 months. Am J Obstet Gynecol 2009;201:160.e1-7.

# GRIEF INTENSE AND PERSISTENT WITH ABORTION

- Cross-sectional study from Netherlands of 253 woman with termination prior to 24 weeks[5]
- Evaluated 2-7 years post-abortion
- Found 5/253 (2.6%) with pathologic grief and 33 (17%) with posttraumatic stress

[5]Korenromp MJ, Christiaens ML, van den Bout J, Mulder EJH, Hunfeld JAM, Bilardo CM, Offermans JPM, Visser GHA. Long-term psychological consequences of pregnancy termination for fetal abnormality: a cross-sectional analysis. Prenat Diagn 2005;25:253-260.

# GRIEF WITH FIRST TRIMESTER SPONTANEOUS LOSS EQUAL TO THOSE WITH LIVE BIRTH

- Prospective mental health for 227 women with first trimester loss and 213 with live birth[6]
- First 6 months increased depression, anxiety, and somatization in loss group
- No difference at one year

[6]Janssen HJ, Cuisinier MC, Hoogduin KA, de Graauw KP. Controlled prospective study on the mental health of women following pregnancy loss. Am J Psychiatry 1996;153:226-230.

# Anencephaly-Lethal anomaly Hospice versus Termination[7]

- Anencephaly in 158 women with 109 male partners
- Used several scales
  - Perinatal Grief Scale
  - Impact Event Scale
  - Beck Depression Inventory II

**[7]Cope H, Garrett ME, Gregory S, Ashley-Koch A. Pregnancy continuation and organizational religious activity following prenatal diagnosis of a lethal fetal defect are associated with improved psychological outcome. Prenatal Diag 2015;35:761-768.**

# Anencephaly-Lethal anomaly Hospice versus Termination

- Women who chose to carry their child with anencephaly:
  - Demonstrated less despair
  - Less avoidance
  - Decreased levels of depression
- Compared to women who chose to terminate their pregnancies.

# SIGNIFICANT GROUP OF PATIENTS TO NOT DESIRE ABORTION

Analysis of 53,000 pregnancies in 2002 (1984-1997) found 20% patients will continue pregnancy no matter the findings.

[8]Schectman KB, Gray DL, Baty JD, Rothman SM. Decision-making for termination of pregnancies with fetal anomalies: analysis of 53,000 pregnancies. Obstet Gynecol 2002;99:216-222.

# MATERNAL MORTALITY RATES SKEWED

- Mortality related to induced abortion at 16-20 weeks gestation is 9.3/100,000 abortions.[9]

[9]Lawson HW, Frye A, Atrash HK, et al. (1994) Abortion mortality,United States, 1972 through 1987. Am J Obstet Gynecol 171:365-372.

- Data from the same time period shows a maternal mortality of approximately 17.3/100,000 live births however data has been disputed.[10]

[10]CDC (2018). www.CDC.gov. Pregnancy Mortality Surveillance System (25 November 2020 last update)

# MATERNAL MORTALITY RATES SKEWED

- Studies show that only 50-70% of maternal deaths may be confirmed as being pregnant prior to the death.[11,12]

[11]Catalano A, Davis NL, Petersen EE, Harrison C, Kiieltyka L, You M, Conrey EJ, Ewing AC, Callaghan WM, Goodman DA. Pregnant? Validity of the pregnancy checkbox on death certificates in four states, and characteristics associated with pregnancy checkbox errors. Am J Obstet Gynecol 2020;269.e1-8.) (70% accuracy)

[12]Baeva S, Saxton DL, Ruggiero K, et al. Identifying maternal deaths in Texas using an enhanced method, 2012. Obstet Gynecol 2018;131:762–9. (50% accuracy)

- 70% accuracy (Catalano et al, 2020)[11]
- 50% accuracy. (Baeva et al, 2018)[12]

# II HOSPICE CONCEPTS: ADULT

**Adult hospice began in 1960's in Britain with Cicely Saunders**

- ✓dealt with nursing/medical issues
- ✓addressed common fear of pain
- ✓prevented withdrawal from patient by family/ staff/physicians
- ✓provided a helpful framework to work through end of life issues in *family centered* manner

# II HOSPICE CONCEPTS: NEONATAL

## Childhood treatment of terminally ill

- Whitfield of Denver Children's Hospital pioneered the concept[13]

[13]Whitfield JM, Siegel RE, Glicken AD, Harmnon RJ, Powers LK, Goldson EJ. The application of hospice concepts to neonatal care. Am J Dis Child 1982;136:421-424.

- implemented neonatal hospice
- neonatal model is simply insufficient for our prenatal patient's needs
- what to do with terminally ill in-utero patients?

# III DEFINITION: “PERINATAL HOSPICE”

Prenatal diagnosis of terminally ill fetus in utero leading to perinatal hospice as part of the continuum of end of life care

# PERINATAL HOSPICE CHARACTERISTICS

- Comprehensive care
  - ✓emotional needs
  - ✓spiritual needs
  - ✓Psychosocial needs
  - ✓medical/obstetric needs
  - ✓care for the entire family
- Multidisciplinary care
- Coordinated care

# IV HOW DONE?

- Understand termination is not an option for all our patients (at least 20%[7] and over 70-80% in our 2 published series[14,15])
- Use decision algorithms based on CONFIRMED prenatal diagnosis!
- Only TERMINALLY ill fetuses are included
- CONFIRM diagnosis!
- Use chromosomes/anatomy surveys

[8]Schechtman KB, Gray DL, Baty JD, Rothman SM. Decision-making for termination of pregnancies with fetal anomalies: analysis of 53,000 pregnancies. Obstet Gynecol 2002;99:216-222.

[14]Calhoun BC, Napolitano P, Terry M, Bussey C, Hoeldtke NJ. Perinatal hospice: comprehensive care for the family of the fetus with a lethal condition. J Repro Med 2003;48:343-348.

[15]D'Almeida M, Hume RF, Jr., Lathrop A, Njoku A, Calhoun BC. Perinatal Hospice: Family-Centered Care of the Fetus with a Lethal Condition. J of Physicians and Surgeons 2006;11(3):52-55.

# HOW DONE? (CONTINUED)

- Comprehensive counseling done
- Focus is on PATIENT and FAMILY
  - ✓accessibility
  - ✓support
  - ✓reassurance
  - ✓compassion not abandonment
  - ✓alternative for patients

# HOW DONE? STAFF INVOLVED

- Perinatal/ neonatal staffs
- Resident/MFM Fellows/Students
- Ultrasonographers (RDMS)
- Nursing (L&D/antepartum/postpartum)
- Social services
- Chaplain services/local pastors
- Grief counseling

# HOSPICE DECISION ALGORITHM

Anomaly Noted

Life Limiting Anomaly

Non-Lethal

Perinatal Hospice

Termination

Prenatal Care

Non-aggressive therapy

Aggressive care

Supportive

no medications
heroic measures

Includes supportive care &
allowing infant to die with family

Interventionist
and intubation
(allows IV fluids, ICU care
considers minor
interventions-i.e.,
closure of hernia, etc)

Full care-surgery

# V RESULTS: MADIGAN SUBSET

- Count at Madigan included 33 patients with fatal anomalies-“Perinatal Hospice” (9/02) with 28/33 (85%) choosing perinatal hospice care
- Patients all positive about hospice care and opportunity to spend time with infants (17/28 or 61% of patients had live births)

# V RESULTS: MADIGAN PATIENT SUBSET DELIVERY INFORMATION

**Delivery Breakdown**

- 17/28 live born (61%)
- 11/28 IUFD's (39%)

**Live born**

- 5/28 cesareans for maternal request /OB indications
- 12/17 live-borns-vaginal deliveries
  - 4 preterm deliveries
  - 8 term deliveries

# V RESULTS: ROCKFORD PATIENT SUBSET

- Count at Rockford (12/2004) included 28 patients with fatal anomalies-“Perinatal Hospice” with 21/28 (75%) choosing perinatal hospice care
- Patients all positive about hospice care and opportunity to spend time with infants (16/21 or 76% of patients had live births)
- Oral presentation of Rockford data at Armed Forces District ACOG Meeting in San Antonio, Tx 10/20/03

# V RESULTS: ROCKFORD SUBSET DELIVERY INFORMATION

**Delivery Breakdown**

- 16/21 live born (76%)
- 5/21 IntraUterine Fetal Demises (IUFD) (24%)

**Live born**

- 1/21 cesareans for maternal request /OB indications
  - Acrania
- 15/21 live-borns-vaginal deliveries
  - 4 preterm deliveries
  - 11 term deliveries
  - Most infants died within minutes to a few days (3 > 2 weeks)

# COMBINED EXPERIENCE RHS AND MAMC

- Range of Infant Lifespan:  20 minutes to 256 days
- Patients & families expressed satisfaction about the opportunity to spend time with their infants
- Religious/spiritual opportunities
- Opportunity for funeral/memorial
- No maternal morbidities/complications
- Mirrors previous experience of Spinnato, et al, 1995[16]

[16]Spinnato JA, Cook VD, Cook CR, Voss DH.  Aggressive intrapartum management of lethal fetal anomalies: beyond fetal beneficence.  Obstet Gynecol 1995;85(1):89-92

# COMBINED EXPERIENCE RHS AND MAMC

- Opportunity for family and siblings to spend time with the affected infant
- Professional satisfaction for care team
- Opportunity for physical examination, autopsy, and genetic testing to confirm diagnosis and guide counseling for future pregnancies

# Validating & Invalidating Provider Behaviors in Mother's Narratives[15]

- Narrative study by Lathrop, 2010 on 15 women with hospice found validating and invalidating provider behaviors[17]

[17] PhD thesis defense April, 2010 by Anthony Lathrop, MSN, RN, CNMA at Marquette University. *A narrative analysis of perinatal hospice stories.*

# Validating & Invalidating Provider Behaviors in Mother's Narratives[15]

| Subject of validation or invalidation | Validating | Invalidating |
|---|---|---|
| Baby | Called baby by name | Used insensitive terminology |
| | Treated baby like a person | Treated baby like an object |
| | Said baby was beautiful | |
| | Attended to baby's needs | |
| | Acknowledged value of baby's life | Emphasized futility & death |
| | US: showed images | US: focused on abnl's |
| | Provided hand/foot models | |
| | Took/facilitated photographs | |
| | Attended memorial | |

# Validating & Invalidating Provider Behaviors in Mother's Narratives[17]

| Subject of validation or invalidation | Validating | Invalidating |
|---|---|---|
| Mother's autonomy | Accepted decision to continue pregnancy | Pressured me to terminate pregnancy |
| | Offered options | |
| | Followed birth plan | Followed routines |
| | Listened before telling | |
| | Respected our privacy | |
| | Allowed time to make decisions | |

# Validating & Invalidating Provider Behaviors in Mother's Narratives[17]

| Subject of validation or invalidation | Validating | Invalidating |
|---|---|---|
| Mother's care giving | Provided unlimited time with baby | Interrupted time with baby for care routines |
| | Helped me bathe baby | |
| | Helped me dress baby | |
| | Trusted me to take care of baby | |
| | Recognized me as a mother | |
| | | Provided inadequate information about baby's care at home |

# Validating & Invalidating Provider Behaviors in Mother's Narratives[17]

| Subject of validation or invalidation | Validating | Invalidating |
|---|---|---|
| Mother's feelings | Did not tell me how to feel | Told me how I should feel |
| | Acknowledged significance of my loss | Expected me to "get over it" quickly |
| | Made human connection | Maintained excessively clinical demeanor |
| | Seemed comfortable with tears | |
| | Treated us like normal people | |

# Perinatal Hospice 2022

- After 20 +years since perinatal hospice first initiated have over 266 programs in US (were 80 in 2010)
  - ✓ hospital/clinic-based
  - ✓ hospice-based
  - ✓ freestanding
- 80 international: Argentina, Australia, Brazil, Canada, Chile, Czech Republic, England, France, Germany, Hungary, Ireland, Italy, Mexico, New Zealand, Nicaragua, Norway, Paraguay, Poland, Scotland, Singapore, South Africa, Spain, Ukraine, Wales
- www.perinatalhospice.org (accessed November, 2022)

# RESOUCES-WORLDWIDE & IRELAND

- Website list www://perinatalhospice.org

# VI CHALLENGES

- Providers:
  - ✓examine our own responses and motivations
  - ✓re-think our care algorithms
  - ✓tendency to withdraw from painful situations
- Institutions:
  - ✓intra-departmental barriers, communication & coordination
  - ✓standard practices & policies

# VI CHALLENGES

- Data collection and research
- Need multi-center experiences
- Centers of excellence may need to be established for hospice care
- Inform patients and communities

# CONCLUSIONS

- Significant number patients (6-10,000/ year)
- Significant patient demand when offered comprehensive alternatives (75-80%)
- No increase in morbidity (may be less)
- Shows our compassion for the most helpless

# QUESTIONS

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# FURTHER INFORMATION


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