Grief Work Following Termination For Anomalies

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Abortion in the United States

- Legal issues
- Religious, Cultural and Regional Issues
- Politics
Abortion For Anomalies

- Congenital and chromosomal anomalies are the leading cause of neonatal death in the US.
- No comprehensive statistics, but it is thought that 80-95% of parents with serious prenatal diagnosis choose abortion.
- A study in Uruguay where abortion is illegal showed 89%-96% of couples aborted for severe chromosomal abnormalities.

Mt Sinai Hospital

- 1,171 bed teaching hospital
- Borders Upper East Side and East Harlem, a very wealthy and a very impoverished neighborhood
- Over 6,700 deliveries per year
- Active obstetrics, high risk, NICU and genetics departments
- About half of all terminations performed are for prenatal diagnosis
The goal is to provide education and support to families from the moment of diagnosis through the initial stages of grief in a manner that respects culture, values and beliefs.

Prenatal Testing and Implications
- Sonogram
- Quad Screen
- CVS, Amniocentesis
- Microarray

Decision Making
- Clarity of diagnosis
- Consensus of professionals
- Severity of diagnosis
- Quality and duration of life
- Family/sibling considerations
- Resources
Options

- D&E vs. Delivery
- Mementos
- Disposition
- Testing
- Memorial

Counseling Goals

- Education re: physical, emotional responses, grief vs. depression, coping strategies, dealing with others
- Normalize struggles, feelings, experience
- Validate
- Provide framework for moving forward

Group Themes

- Betrayal
- Guilt
- It’s not a miscarriage
- What if...
- Medical experience
- Couples grieving differently
Group Themes

- The rest of the world is pregnant and happy; don’t they know what can happen?
- Fear of trying again
- How can you grieve when you’ve made the decision?
- Coping strategies
- Politics, news

Group Composition

- Mostly second trimester
- Tend to be highly educated professionals
  - First or second pregnancy
  - Often in individual therapy either prior or subsequent to termination
- Men and women attend

Group Dynamics

- Group runs itself
- Members have never before met anyone else going through this experience
- Members share experiences, validate each other and share coping strategies
- Open ended, monthly, members come when they need to.
- Even one session provides marked relief
Perinatal Grief Scale

1. I am grieving for the baby
2. I find it hard to get along with people
3. I feel empty inside
4. I can't keep up with my normal activities
5. I feel a need to talk about the baby
6. I am frightened
7. I have considered suicide since the loss
8. I take medicine for my nerves
9. I very much miss the baby
10. I feel depressed

11. I feel I have adjusted well to the loss
12. It is painful to recall memories of the loss
13. I get upset when I think about the baby
14. I cry when I think about him/her
15. I feel guilty when I think about the baby
16. I feel physically ill when I think about the baby
17. I feel unprotected in a dangerous world since he/she died
18. I try to laugh, but nothing seems funny
19. Time passes so slowly since he/she died
20. The best part of me died with the baby
21. I have let people down since he/she died
22. I feel worthless since he/she died

23. I blame myself for the baby's death
24. I get cross at friends and relatives more than I should
25. Sometimes I feel like I need a professional counselor to help me get my life back together again
26. I feel as though I'm just existing and not really living since he/she died
27. I feel so lonely since he/she died
28. I feel somewhat apart and remote even among friends
29. It's safer not to love
30. I find it difficult to make decisions since the baby died
31. I worry about what my future will be like
32. Being a bereaved parent means being a "Second Class Citizen"
33. It feels great to be alive
Predictors of Coping

- Pre-loss neuroticism is predictive of grief intensity at both 2 months and 2 years post loss
- Perceived supports from family and friends, strong relationship with partner = lower scores
- Support and counseling after perinatal bereavement significantly decreases psychiatric symptoms
- Early subsequent pregnancy < 6 months significantly increases psychiatric symptoms
- 25% have PTSD 1 month post loss, 7% after 4 months
- 10.9% have a major depressive disorder within 6 months of loss, 2.5x community rate

Factors in Grieving

- Gestational age is not necessarily a predictive factor in the impact of loss or the grieving process
- Strong religious belief can offer some protection against or alternatively increase feelings of helplessness and guilt
- Detailed information about the grieving process helps families feel in control and normalizes experience
- Every loss is impacted by previous losses of any kind
- Grief lasts a lifetime

A MODEL FOR PERINATAL PALLIATIVE CARE: PREPARING MOTHERS AND FAMILIES TO SAY “GOOD-BYE” AT BIRTH

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DISCLOSURES
Written consent was received to present the photographs, correspondence, and patient stories used in this presentation.

WHY DO FAMILIES CONTINUE?

WHAT IS PERINATAL PALLIATIVE CARE?
- “Hospice in the womb”
- Multidisciplinary team approach
- To embrace whatever life a baby might have, before and after birth
- Including birth planning and preliminary medical decision-making before the baby is born
- Enables families to make meaningful plans for the baby’s life, birth, and death, honoring the baby as well as the baby’s family
- More traditional hospice and palliative care after birth (if the baby lives longer than expected)

Perinatalhospice.org
INTEGRATIVE MODEL OF PALLIATIVE CARE

Figure 1. Integrative model of curing and healing. Copyright 2010, Jay Milstein. Modified by Rana Limbo and Kathie Kobler.

CHILDREN’S HOSPITAL OF PHILADELPHIA CENTER FOR FETAL DIAGNOSIS AND TREATMENT (CFDT)

- High risk fetal and diagnostic center
- First of its kind labor and delivery unit located within a freestanding tertiary-care pediatric hospital
- Dedicated to healthy mothers carrying high risk fetuses
- 400-450 births annually
- ~2700 births to date

The Garbose Family Special Delivery Unit Est. 2008

CFDT PERINATAL PALLIATIVE CARE AND BEREAVEMENT PROGRAM

Our program provides a multidisciplinary collaboration to support families diagnosed with life-threatening fetal anomalies from the point of diagnosis beyond the death of their baby
HELPING FAMILIES PREPARE FOR THEIR LOSS

• Anticipating the needs of the mother and family within all the phases of the perinatal palliative care process:
  1) diagnosis, pregnancy management options, and family decision making
  2) continuing the pregnancy and follow-up throughout the prenatal period
  3) birth planning process
  4) the baby’s living and dying
  5) early postpartum period and post-mortem

• The overall goal: to partner with a mother and her family in order to provide individualized, seamless and compassionate care throughout the prenatal and postpartum course

REFERRAL FOR PALLIATIVE CARE CONSULTATION

• Maternal Fetal Medicine physician is often the initial point of contact
• Introduction of pregnancy management options
  – Termination of pregnancy
  – Continuation with heroic measures
  – Continuation with palliative care
• Family self-referral
• As fetal condition changes, team may determine a different path of care

THE PALLIATIVE CARE CONSULTATION

• Family meets with the Neonatologist, Psychologist and Social Worker as early into care as possible
• Validate the family’s experience of becoming parents under challenging circumstances
• Explore the clinical paths that the baby might take
  – What would intensive care look like?
  – What would palliative “comfort” care look like?
• Elicit the family’s understanding and values
• Guide the family in medical care choices consistent with their goals and values
• Demonstrate honest provision of information
INTEGRATION OF PSYCHOSOCIAL SUPPORT SERVICES

Options Counseling
• Support a couple’s decision to terminate or continue
  Grief counseling, spiritual support, resources, psychoeducation
• Offer consistent follow-up for families who experience loss and connect them with grief resources in their communities

Development of Palliative Care Birth Plan
• Help parents and siblings plan for and cope with the remainder of the pregnancy and beyond the death
• Work to bolster the entire family’s coping strategies to prevent subsequent PMADs or acute traumatic responses

THE THERAPEUTIC PROCESS OF BIRTH PLANNING
• Engage family in a therapeutic process to support their grief and create a safe space to discuss their thoughts and feelings
• Partner with a patient/couple in their process
  – Going at their pace in the couple’s decision making (ongoing revisions)
  – Empowering both parents in the discussion
  – Attending to their needs and fears (exposure techniques)
  – Balancing the celebration of life while preparing to say “good-bye”
  – Maintaining focus on self-care and symptom management
  – Providing parents with language for older siblings
  – Referral to grief counseling prior to death
• Organize the family’s wishes into a comprehensive birth plan to be available to the medical and nursing teams within the maternal MRN

SIBLINGS: LANGUAGE TO EXPLAIN DEATH
• Partner with parents to find language that feels comfortable for them to use
• Concrete, simple and honest information
• Avoid abstract terms such as “went away,” “passed away,” or “we lost the baby”
• Avoid the term “sick” instead focus on growth or lack thereof
  – “Our baby did not grow big enough in mommy’s belly.”
  – “The baby’s lungs did not grow big enough and the baby died”
• Provide reassurance, “Sometimes this happens with babies and we don’t know why. Nobody did anything wrong and Mommy and Daddy are okay.”
TEAM ACCESS TO BIRTH PLAN

• Birth Plan is located in Maternal EMR
• Outpatient and Inpatient team access
• Open dialogue about family’s wishes
• Make changes at each appointment
• Fluid/Open document (closed after death)

IMPACT OF PSYCHOSOCIAL PREPARATION FOR L&D STAFF

• Streamlined processes for the team
• Decrease risk of traumatic birth exposure
• Increase focus on clinical measures
• Culture of empowerment regarding death
• Support a therapeutic environment for patients and staff
ENGAGING FAMILIES IN THE HEALING PROCESS OF MEMORY MAKING

- Foot and hand molds
- Ink prints
- Paint prints
- Lock of hair
- Photography
- Parent and sibling ideas

BEREAVEMENT PHOTOGRAPHY

PREPARING FAMILIES TO GO HOME

- Leaving the security of the hospital and care of staff
- Use written information/instructions whenever possible
- Follow up post-discharge is essential to help maintain the healthy grieving that started while in the hospital
  - Recommendation one week post-discharge for phone call
- Making a post-discharge self-care plan
  - Attending to physical health
  - Helping re-establish daily routine
  - Allowing protective time at home
- Being in the home without the baby (e.g., nursery items)
- Returning to work (e.g., telling others, pacing oneself upon return)
ANTICIPATING POSTPARTUM NEEDS

- Dealing with hospital bills and death certification after the loss
- How to express grief to others
  - Answering the hard questions
- Finding support (online, therapy, groups)
- Coping with physical changes
  - Body no longer being pregnant
  - Breast milk production
  - Return of menstruation
- Re-engaging in sexual intimacy
  - Addressing birth control options

However, when couples and families are supported...

PROVIDER’S ROLE IN EMOTIONAL HOLDING

- Honoring and Witnessing
  - Honor the birth and time spent with baby
  - Being fully present (containment; emotional holding)
- Honoring the patient/family pacing
- Engaging family in connecting with baby
- Being comfortable in the silence
- Difference between “doing to” and “being with”
- Containing the experience with the family
CARE FOR THE CAREGIVERS

- Face your own thoughts and feelings about death
- Educate yourself about the grief process
- Organize staff support
- Debriefing and Peer consultation
- Setting personal/professional boundaries and limits
- Personal awareness of triggers to avoid compassion fatigue

National Board for Certification of Hospice and Palliative Nurses  [www.nbchpn.org](http://www.nbchpn.org)
Resolve Through Sharing: Perinatal Death  [www.bereavementservices.org](http://www.bereavementservices.org)

THANK YOU!

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