

Perinatal Loss, the Subsequent Pregnancy and Child

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Importance of Topic for Family Educators

Although the experience of infant loss occurs within the medical setting it is the community and family educators who see the impact of these losses on families

How many families are impacted by loss?

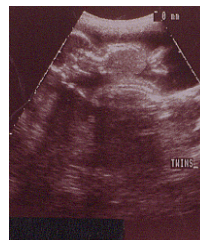
- 25 % of all pregnancies end in loss in the form of miscarriage, stillbirth or neonatal death
- African American women experience loss 2x more frequently than European Am. Women
- 3% of pregnancies result in children with special needs
- 59 to 86% of families have another pregnancy and previous loss is a risk in the next pregnancy

- Pregnancy after stillbirth is a stressor for post-traumatic stress disorder.
- Heightened fear and anxiety affects the health care and emotional needs of the parents and can have long term affects on the mental health needs of the subsequent child.
- Historically, children born after a loss were described as "replacement children" or having Vulnerable Child Syndrome."

Miscarriage occurs in 1 of 5 pregnancies.

- Continues to be regarded as an insignificant event by lay and professional community yet depression after miscarriage is a significant clinical problem
- Often brings a sense of loss of control and helplessness
- In a 1993 study 71% of women considered their miscarriage a baby with 94% having this viewing in 1996

Reproductive technology has increased the occurrence of loss in multi-fetal pregnancy



- As many as one in ten births start out as twin pregnancies.
- Between 1% & 20% of pregnancies induced by fertility drugs result in 3 or more fetuses.
- The spontaneous loss of one or more fetuses in a multiple gestation may be as high as 30%.

The Families Perception of Loss is influenced by:

- Communication skills of the family, including intergenerational
- Who died and what relationship a person had
- The history of loss and death in the family
- The developmental level of the sibling
- Manner and cause of death

Impact on Family Life

- The security and vulnerability of parental identity is tested, potentially impairing interactions with all their children.
- It is always a part of the family story, thus becomes part of the siblings story.
- Relationships are changed for the immediate family as well as extended family.
- Protective parenting is a common.

The Parenting Experience of Loss

- What happens to the normal tasks of pregnancy
- Role as a mother, father, sibling?

“The course of the parent’s development is derailed...a deprivation of one’s instinctual urges to both give and receive, to nurture and grow, to feed and be fed. A specific person who can never be replaced has died.” (Leon, 1990)

Providing Support

- People in mourning need our support. In times of sorrow, one word, one gesture, can mean everything
- Reach out and acknowledge their loss. “I am so sorry.”
- Affirm their roles as parents from the moment of conception
- Even if you have not experienced a prenatal loss your self, let parents know you are there to help or listen
- Ask if they named the baby
- Ask how siblings are doing
- Understand that men and women grieve differently

Children and Grief



A child can live through anything, so long as he or she is told the truth and is allowed to share with loved ones the natural feelings people have when they are suffering.

Eda LeShan

Involving Children



Everyone told me Dustin, who was 3 years old, wouldn’t understand what was going on because he was so young and that he probably won’t even remember. But he was the one who forced me once a week to take him to the grave the first year and a half.



The Importance of Fathers



- A fathers' role during pregnancy continues to be unclear other than as a "support person"
- Fathers are essential to family health and well being and influences a child's development into adult life
- Men asked to identify the moment they felt they were fathers. Two men shared the experience of the first ultrasound; one saying "He's mine" and the other one "We did that!"

Fathers and Grief

- Grief is much less culturally acceptable for men
- They often report the need to hold it together for the sake of their wives
- Denial is the main coping mechanism when confronting their loss
- Fathers have less intense grief reactions to prenatal losses and tend to grieve more for what will never be rather than what was lost.
(Rowa-Dewar, nd; Hill, 2003; Schwab, 1996, Wheeler, 2001)

Fathers and Grief

- Measurement of grief is biased because of gender stereotypes. Scales focus on emotional reactions.
- Due to cultural norms, men's requests for help may go unrecognized.
- May be more angry and aggressive
- Increase use of alcohol
- Drown themselves in work
- Men are more heavily affected by grief 12 to 15 years after the loss.

Remembering: Grief vs. Trauma

- Grief is remembering the deceased as part of the course of adaptation, reorganization and recovery.
- Traumatic memories may be overwhelming and sufficiently stressful that they cannot be integrated without assistance.

Traumatized individuals cannot embrace the process of grieving until they are given the opportunity to process the primal emotions associated with trauma and then make new meaning of their life experience.

Making Meaning

- In order to make meaning out of the loss, families must tell their story (Nadeau, 1998)
- The parental journey to make meaning out of the loss of their child is the most important step on their road to coping with the loss itself. (Wheeler, 2001)
- It is important to keep "symptoms" for illness. Grief is not an illness.
- Grief is resolved through the creation of a loving, growing relationship with the dead that recognizes the new psychological or spiritual dimensions of the relationship. (Shapiro, 1996, Attig, 2001).

Examining Infant Loss Using Attachment Based Theory

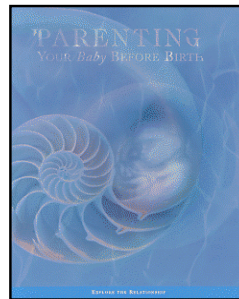
- Attachment is a unique relationship between two people, specific and enduring over time
- Maternal-fetal attachment...represents the development of the earliest, most basic form of human intimacy..." (Condon & Cortindale, 1997)
- When attachment definitions include an element of time there is the potential risk for minimization of a perinatal loss (Robinson, et al., 1999)
- Viewing infant loss and the subsequent pregnancy from a model of **prenatal** attachment honors the parents sense of self in a relationship with their children.

Subsequent Pregnancy/Child The Need for Education

"...it's about grief management, because being pregnant again is the biggest reminder of the greatest loss a mother will ever experience."

(Mother in second pregnancy)

Intervention based on the work of Selma Fraiberg's "Ghost in the Nursery"



- Parents need to trust the process of pregnancy again and embrace the new baby
- Education makes the presence of a baby real while honoring their parenting role to the baby who died
- Parents supported by others who respect this have lower rates of depression and less chance of grief becoming "pathological"

Themes: We are changed people

- A new definition of pregnancy
- Fear and anxiety
- Loss of innocence and trust
- Worry and stress
- Control to Protect

Developmental Tasks of Subsequent Pregnancy

- Working with the fear of another abnormal pregnancy
- Avoiding attachment for fear of future loss
- Moving past the unwillingness to give up grieving out of loyalty to the baby who died.
- Grieving the loss of self-the self that is parent
- Attaching to the unborn child separately from the child who died
- Some families have an additional task: **Fear of maternal death.** (O'Leary & Thorwick, 1994)

Parenting Issues

- **Protective Parenting Begins During Pregnancy** "I over-analysis everything. If the baby hasn't moved for two hours I call the doctor."
- **Symptoms of Post-traumatic Stress Disorder** 21% of women reporting stillbirth had PTSD symptoms in third trimester of next pregnancy. (Hughes, et al, 2003).
- **Attachment to the Subsequent Child** 45-65% of children born after a loss have attachment disorders at one year postpartum (Heller & Zeahan, 1998; Hughes & Fonagy, 2000; Hughes, et al, 2003)

Attachment Issues

"They didn't ask to be born after a loss."

- **Cautious in attaching.** I don't want to attach because I don't want to get hurt, yet if I don't attach that's not fair to the baby.
- **Separating this baby from the previous baby.** "I think the thing that might be the hardest for me, I realize this is a whole different baby and it's a boy."
- **More conscious of fetal movement** When you feel the baby move, you think, 'My God, it's still alive!'

Men's Themes

- **Recognition** "They want to see how mom is doing...it's affecting me too."
- **Preoccupation** "You take it to bed with you."
- **Stoicism** "I don't let her know what I'm thinking."
- **Support** "He was trying to take care of his family."

Stoicism

"We can't have two people breaking down in the same family. I could hide my emotions because if I broke down in front of her too...what good's that going to do?"



PTSD symptoms with Dad



Involving the Children in the New Pregnancy

- Children can have the same fears as the parents.
- "Is this baby going to die too?"
- May worry about the health of the mother.
- Need reassurance that the doctors are taking good care of the baby and their mother.

Siblings

I just say to him—look we hope it will be alright but we just don't know. So I'm waiting to go in and he says "Will it be alright mommy?" They were watching some video and someone was crying. Nicolas out of the blue said "Ah mommy you were crying when you lost your baby." So he's obviously got a good memory and remembers.

Postpartum Issues

- Breast feeding can be more difficult
- New layer of grief is common
- The new baby does not take away the memory of the other baby.
- Parents still need to talk about the other baby but friends and family want them to be "normal" again.
- Fear of this baby dying may intensify. Be aware of "normal" postpartum issues that will alarmed them.

"I never expected him to make our loss any better but I didn't expect him to magnify the loss."

"I thought that void I felt would be filled a little but it didn't seem to matter. The grief was still there."

Protective Parenting Behaviors

- Hyper-vigilant behavior of the baby's movements during pregnancy
- Fear of leaving their children with others
- Worry about the safety of living children
- "I wouldn't let anybody else hold her. I didn't have a baby sitter until she was a year old."

Themes from Study of Adult Subsequent Children

Participants: 7 Women 2 Men

- Invisible
- Protecting their mother from pain
- Role reversal
- Empathy

Invisible

- I'd always felt like my mother and I weren't really connected. That played out in my own life as feeling like I was a disappointment. And that I was invisible.
- I hid to be visible. I think it was something about drawing attention rather than hiding to actually be invisible.

Role Reversal

My way of coping with life was to become very quiet and a servant, doing whatever I could to keep peace.

In many ways she was my parent but I have always been hers as well.

Protecting their mother from pain

I knew as a child I must try to do everything I could not to die so as not to hurt my mum. I became obsessed with her happiness, buying her little gifts or doing things for her but her sadness is chronic. She can be happy but not happy from her heart in the way most other people can be. Hers is a deep, deep sorrow.

Empathy

- I am drawn to grieving people
- I understand their need to be recognized
- All except one adult work in the helping profession

I would say she has an empathic spirit as a child.

Can you give some examples of that?

She just will come up to me and say, 'Mom you seem kind of sad today. What can I do to make you happy?' She'll do that even with her brother and sister and friends, other family members. She just has a heart for other people when they're sad, what she can do to make them feel better. But even in the womb, she was like that. I can count probably more than twenty or thirty times when I was nervous, especially later in pregnancy, about her not being okay or not having felt her kick for awhile and she would kick.

Impact on Alexis

- We were very open with Alexis
- She would talk to and see her sister when she was young
- Experiences bouts of sadness, often at pre-school
- Often speaks of wanting a younger sister
- Later death of great grandmother difficult
- Her drawings of our family often contain an angel



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Preventing Disenfranchised Grief



- Children who know the story keep the child in the family
- They will not have a disenfranchised grief if the deceased child is talked about in the family. It is not a secret.

Keeping the Memory Alive

- On his birthday we usually go to his grave site and visit him.
- We have pictures of Bailey so he's a part of our life.
- We buy a present at Christmas for how old she would be and the kids get to pick it out.

Comfort with Death at Three and Four

- They're very comfortable with death. They talk about it, process it and they get it that their gone. They ask questions but they're not anxious or worried. They don't go into the fear based stuff around death. "Are you going to die and what will happen to us?" They go more into what happens spiritually to people when they die.
- For both my kids death is like, "Oh, you get to see my brother! Natalie's teacher's dad died and she was gone for two weeks. When she came back Natalie said, 'Mom said your daddy died. 'He gets to be with my brother!'"

Siblings are affected too

<p>My brother had been very close to Christine. His grief was very much overlooked and spent a great deal of his time living with my grandparents after Christine had died. He is fifty three years old and lives alone, working mostly in solitary jobs. He has one close friend.</p>	<p>Within the context of loss common patterns and reactions of grief emerge throughout life. We all rework pieces of our grief over the lifespan. Reconciling and healing is a process, not an event.</p>
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Impact on Grandparents

As an adult I learned from my mother that my Gran and grandpa's sex life finished after Christine's death. I don't know why I was told this or why I feel I need to share it now but it just feels really sad thinking that the grief was so deep it took away their ability to connect with each other.

My grandfather died of a heart attack. And my grandmother said to my mother, "Your father has never been able to sleep since Mary died. (of SIDS) He died of a broken heart." (*He had found Mary in her crib*).

How you can help

- Provide a support group during pregnancy to help them process their parenting feelings of grief over one baby as they attach to a new baby. Include the fathers!
- Parents have the potential for problems in their future parenting if the psychological implications of loss and attachment are not considered together.

Format

- Open-ended.
- Keep your focus on the age of each baby in the group and the stages of parenting the parent is in.
- Facilitate the parenting relationship of the baby who has died and the baby who is coming.

Strength of the Open Gestation of Pregnancy

- People at different gestations of pregnancy will help each other with developmental stages.
- People come in their uniqueness and find their commonality.

Confidentiality

- What is said in group stays in group.
- As facilitator your role is not to report back to care providers; that is the responsibility of the parent.
- Avoid judging of care.

Facilitators Role

- Listen empathetically
- Probe gently for feelings
- Don't be afraid of silence. Wait. There is always someone else in the group who is more uncomfortable than you.

- Engage in helping families problem solve using the group process
- Ask other group members, "Does that sound familiar to any of you?"
- Facilitate the group members helping each other rather than you being the "expert."

A support group is **NOT** a risk-free intervention.

- Keep balance in the group.
- Be aware of your boundaries; your role as an educator or nurse changes when you are a facilitator.
- Avoid rescuing or fleeing; your job is not to "fix" but reflect back feelings.
- It is the families pain and story, not yours to take on.
- Be aware of your own comfort level around loss.

Self Care of the Facilitator

- Co-facilitate with a peer; if possible one who compliments your background.
- Process after group when possible.

Closure

- It is “the memory that group members take with them” (Bowman, 1995)
- Parents need to come back to the present and acknowledge the babies who are in the room

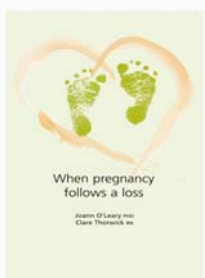


Remember

- There are no magic phrases, but whatever you say will work magic in letting them know you care.
- By truly listening to these stories we can come to understand both the unique nature of the individual journey as well as the common threads this experience has woven into their lives.

A Family's Story

When Pregnancy Follows a Loss: Preparing for the Birth of Your New Baby



Available through:
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