



## *“A Person’s a Person No Matter How Small”* Thoughts on Perinatal Bereavement

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- I am an employee of Prolacta Bioscience
- I currently present and receive financial reimbursement
  - Prolacta Bioscience
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- **Behavioral Objectives**

- *At the conclusion of this presentation the learner will be able to:*
- Discuss the statistics and definitions encompassing perinatal and neonatal loss.
- Define the term “disenfranchised grief” and its application to perinatal loss experiences.
- Describe the concept of “complicated grief” responses.
- Identify sources of support for families experiencing perinatal loss.



**Some Definitions**





## Some Definitions

### • Grief

- Grief is the normal emotional process of reacting to a loss.
- Grief may be experienced as a mental, physical, social or emotional reaction.
- Grief processes depend on the relationship with the person who died, the situation surrounding the death, and the person's attachment to the person who died.



## Some Definitions

### • Bereavement

- Is the period after a loss during which grief is experienced and mourning occurs.
- The time spent in a period of bereavement depends on how attached the person was to the person who died, and how much time was spent anticipating the loss



## Some Definitions

### • **Mourning**

- The process or activity by which people adapt to (survive) a loss.
- Mourning is influenced by cultural customs, rituals and society's rules for coping with loss.
- The mourner's roles, identity and skills may need to change to readjust to living in a world without the person who died.



## Perinatal Loss

### • **Defining Perinatal Loss**

- ? Infertility
- Ectopic pregnancies
- Miscarriage
- Therapeutic termination
- Stillbirth
- Periviable birth
- Neonatal death
- SUPC: Sudden Unexpected Postnatal Collapse
- SIDS: Sudden Infant Death Syndrome



## Disenfranchised Grief

- **Disenfranchisement and Perinatal Grief**

- The juxtaposition of their grief with society's minimization may often **disenfranchise** them from traditional accepted deaths and grieving processes.

*Stupid things  
folks say to  
grieving people...*

Lang, A., Fleischer, A. R., Duhamel, F., Sword, W., Gilbert, K. R., & Corsini-Munt, S. (2011). Perinatal Loss and Parental Grief: The Challenge of Ambiguity and Disenfranchised Grief. *OMEGA - Journal of Death and Dying*, 63(2), 183-196. <https://doi.org/10.2190/OM.63.2.e>

*"I wanted you more  
than you will ever  
know, so I sent love  
to follow wherever  
you go".*

*Wherever You Are,  
My Love Will Find You.*

- Nancy Tillman (2012)





## Disenfranchised Grief

### • Disenfranchised Grief

- Perinatal loss is generally viewed as a less traumatic or prolonged experience than the death of an older child or an adult.
- Perinatal loss has been characterized as an **ambiguous loss**, stemming from the concurrent physical absence of and psychological presence of the fetus or infant

Boss, P. (2004b). Ambiguous loss research, theory, and practice: Reflections after 9/11. *Journal of Marriage and Family*, 66(3), 551-566.  
Cacciatore, J., DeFrain, J., & Jones, K. (2008). When a baby dies: Ambiguity and stillbirth. *Marriage and Family Review*, 44(4), 439-454



## Disenfranchised Grief

### • Disenfranchised Grief

- This sense of ambiguity has the potential to be further compounded by society's dismissal of such a short-lived or even "unborn" life.
- ***"Many people find it hard intuitively to understand why the grief for a child)who has not lived long enough to define him—or herself should be so prolonged or intense".***

Rubin, S. S., & Malkinson, R. (2001). Parental response to child loss across the life cycle: Clinical and research perspectives. In M. S. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 219-240). Washington, DC: American Psychological Association.



## Disenfranchised Grief

- **Disenfranchised Grief**

*“The raw material feeding the grieving process is scarce or absent after perinatal loss. Grieving demands recollecting the sights, sounds, smells, and touch of the beloved—the favourite chair in which he would sit the sound of his laughter, and the image of his smile.*

*When the unborn child dies, there is so little to grieve. . . . So much of perinatal loss involves grieving the loss of the future: relinquishing the wishes, hopes, and fantasies about one who could have been but never was (but briefly).”*

Lang, A., Fleischer, A. R., Duhamel, F., Sword, W., Gilbert, K. R., & Corsini-Munt, S. (2011). Perinatal Loss and Parental Grief: The Challenge of Ambiguity and Disenfranchised Grief. *OMEGA - Journal of Death and Dying*, 63(2), 183–196. <https://doi.org/10.2290/OM.63.2.e>



## Disenfranchised Grief

- **Sources of Ambiguity**

- Ambiguity emerged in different forms and circumstances to contribute to the suffering of bereaved couples.
- This variety included ambiguity
  - About the viability of the pregnancy
  - About the physical process of losing the pregnancy
  - Around arrangements for the remains
  - In sharing the news of the loss



## Mourning



## Disenfranchised Grief

- **Disenfranchised Grief**
- Ambiguity and disenfranchised grief stem from a variety of sources in the possibly unintentional, yet constraining, beliefs of family, friends, society in general, and specifically of healthcare professionals.
- These beliefs seem to amplify couples' negative experience and appraisal of the situation, as well as fuel their perceptions of poor health care provider support.





## Disenfranchised Grief

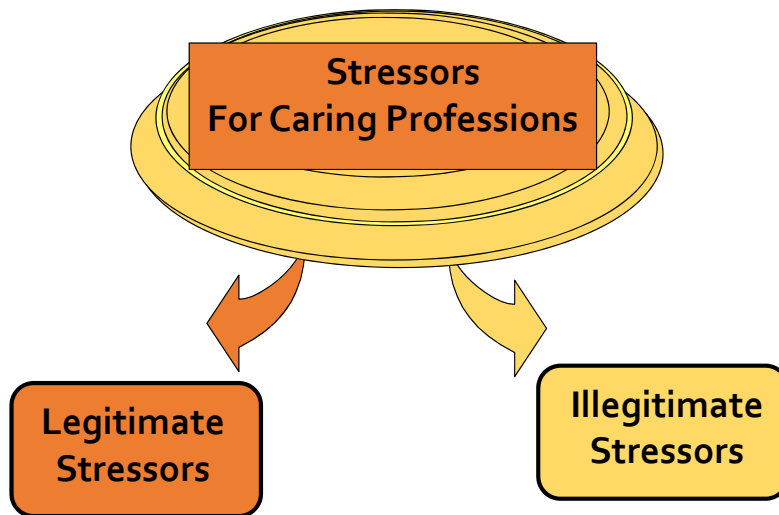
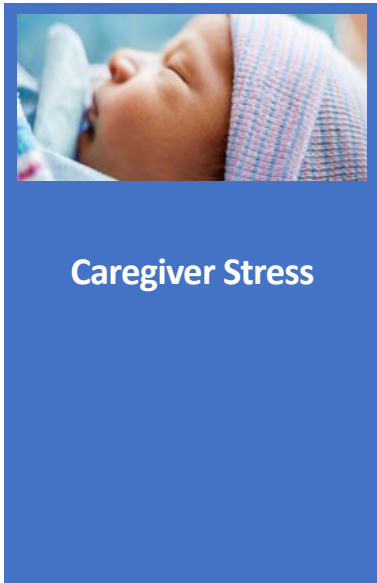
- **Disenfranchised Grief**
- Ambiguity, ambiguous loss and the sense of feeling disenfranchised not only impede bereaved parents' psychological wellbeing and efforts to cope and move forward, but also significantly compromises marital, family, and other relationships.
- The experiences and expression of suffering differs between spouses. The more the wife shows her grief, the more the husband tends to withhold showing his grief, to suffer internally or silently in order to protect or comfort his wife. The more he withholds and suffers internally or silently, the more isolated and misunderstood the wife may feel which increases her suffering



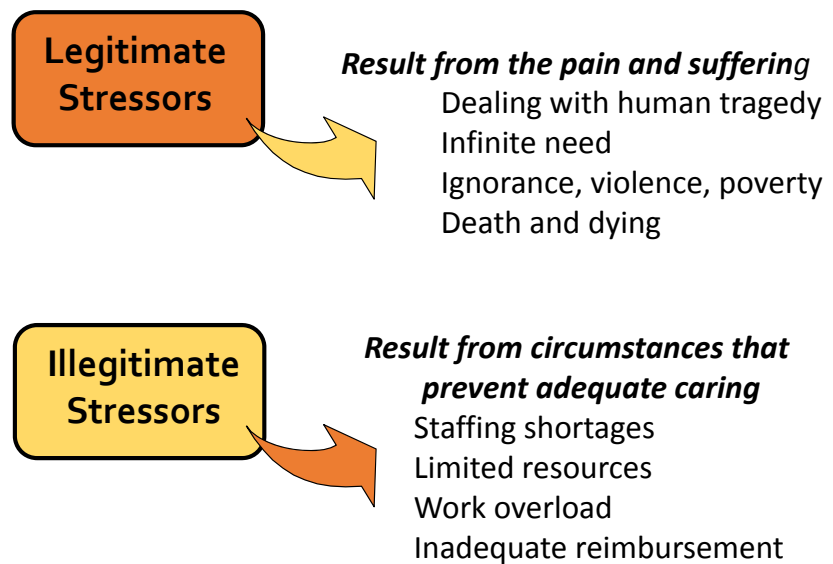
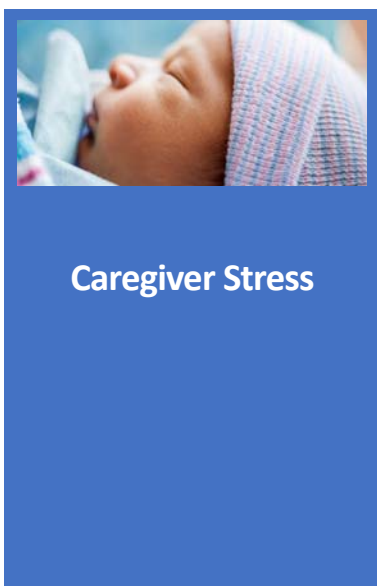
## Caregiver Needs

- **Caring for the “Least of These”**

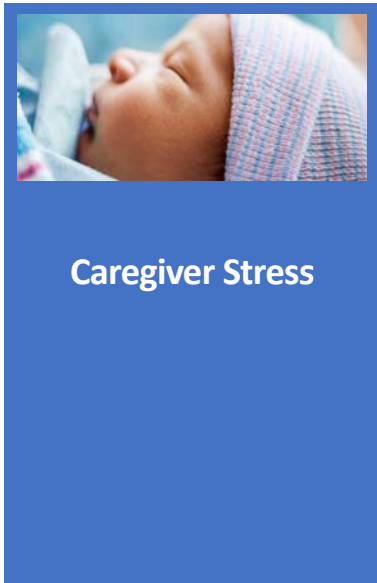




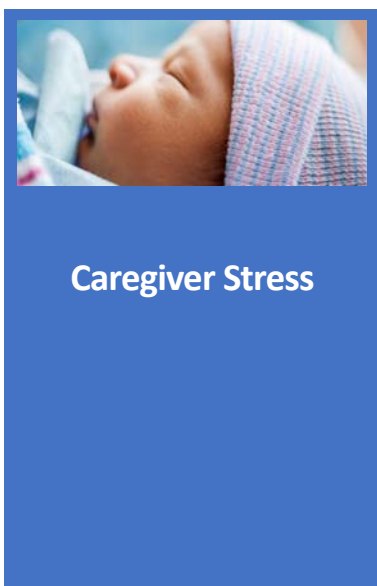
Benner, P., & Wrubel, J. (1989). *The primacy of caring: stress and coping in health and illness*. California: Addison-Wesley Publishing



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- It Has Many Names
- Burnout
- Compassion Fatigue Syndrome
- Helper's Secrets
- "Secret Keeping"
- "Helper's Pit"
- Vicarious Traumatization
- Traumatic Stress
- Rule Number Two



Exhausted, Depleted,  
Numb



Delivering Self"  
as Product

Vertically III  
Horizontally III



## Caregiver Stress

### • Symptoms Include

- Withdrawal
- Inappropriate anger or irritability
- Inability to enjoy life
- Overwhelmed by endless tasks
- Chronic fatigue
- Rigidity
- Sense one's work has become meaningless
- Shortened attention span
- Headaches, GI symptoms
- It Has Many Names



*“You are my angel,  
my darling, my  
star...and my love  
will find you,  
wherever you are”.*

*Wherever You Are,  
My Love Will Find You.*

- Nancy Tillman (2012)





**Contact  
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