

Research Protocol

Title: How Grandparents Incorporate the Existence of a Deceased Grandchild

Investigators: Nina Bennett, MS, Melanie Chichester, BSN, RNC

Purpose: To explore how bereaved grandparents acknowledge the existence of a deceased grandchild.

Background: Contemporary grief theory supports the concept that grief is a lifelong process, and that it is normal to desire a continuing connection with the deceased (Neimeyer). Grieving is seen as finding a way to let go of the pain while honoring the memory (Woolfelt). Bereaved parents and grandparents frequently report that their greatest long term concern is that others will forget their child. A baby who died during pregnancy, at delivery, or shortly after delivery may not be openly acknowledged (Doka), making this concern especially significant. As time passes, grandparents often search for ways to incorporate their dead grandchild into their family in a manner which permits recognition and remembrance. The purpose of this survey is to collect information on how grandparents with a perinatal loss include their grandchild with the intent to share the findings by publishing articles and developing workshops for bereaved families and care providers.

Methods: Bereaved grandparents who are registered members of Alliance of Grandparents, A Support in Tragedy (AGAST, www.agast.org) will be invited to participate in a survey study. AGAST is an internet-based support group for bereaved grandparents, with several active forums. The Principal Investigator has received permission from the Executive Director of AGAST to post an invitation to participate in the survey on the News and Events forum. Beginning September 1, 2008, on the "News & Events" page of AGAST, a posting with the title "Your help is needed" will be placed, with a subtitle "remembrance survey." Under this link will be the invitation/explanation letter and the survey. The posting will remain up for 6 months; we hope to recruit up to 100 participants. If at the six month mark, less than 50 surveys have been returned, then the posting will remain on the website for an additional 6 months. The post will be "pinned" so that it remains at the top of the forum (and not be moved further down the postings as new topics are posted). The PI will assume responsibility for ensuring that the posting remains in place. Participation in this survey is voluntary, and no direct, individual contact will be made to AGAST members. Subjects may return the survey by e-mail or postal mail. E-mail responses will be printed without any identifying information, and responses received through the post will have any potentially identifying information, such as return address, removed. Subjects will be questioned about ways in which they remember and acknowledge their grandchild. Participants will be assured that their responses will be confidential, and that they will not be identified personally. (Survey attached)

Inclusion Criteria: Bereaved grandparents between the ages of 35-80 whose grandchild died during pregnancy, at birth, or within 4 weeks of birth; able to read and write English.

Exclusion Criteria: Anyone who is unable to read and write English; grandparents whose loss was not perinatal.

Benefits/Risks: Answering the questionnaire may bring up feelings of grief over the previous encounter with perinatal loss or personal loss of a child; however, most grandparents come to this website for peer support and have stated that these feelings never really go away and they generally feel better being given the opportunity to talk about their experiences.

Participation in the study is voluntary and there are no consequences to those who visit the website but choose not to participate. The only costs to participants would be if they choose to return the survey via USPS, which would incur the cost of an envelope and 42¢ for postage. There is no compensation for participants other than the knowledge that they may be educating professionals to help other perinatal loss families.

Data analysis: Demographic information will be presented as mean and range. Qualitative answers will be sorted into areas of commonality.

References:

- Bennett, Nina. (2005) *Forgotten Tears A Grandmother's Journey Through Grief*. Delaware: Booklocker.com, Inc.
- Berman, Michael, M.D. (2001). *Parenthood Lost Healing the Pain After Miscarriage, Stillbirth and Infant Death*. Westport, Connecticut: Bergin & Garvey
- Doka, K. J. (Ed) (2002). *Disenfranchised Grief: New Directions, Challenges, and Strategies for Practice*. Champaign, Illinois: Research Press.
- Doka, Kenneth J. (1996) *Living with Grief: After Sudden Loss*. Bristol, PA: Taylor & Francis
- Golden, Thomas R. (2000) *Swallowed by a Snake: The Gift of the Masculine Side of Healing*. MD: Golden Healing Publishing LLC
- Neimeyer, R. A. (2001). *Meaning Reconstruction & the Experience of Loss*. Washington D.C. American Psychological Association.
- Woolfelt, Alan (2004) *Five Common Myths About Grief*. Grief Digest, Vol.2 Issue 1