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Catherine Overson

*University of New Hampshire*

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research ARTICLE

## Perinatal Loss: Its Challenge to Nurses and Educators

—Catherine Overson

Many couples today wait longer to conceive and then carefully choose the size of their families. Given the advances in modern medical technology, few women anticipate a pregnancy outcome that is less than optimal. Despite medical advances, however, every pregnancy does not produce a healthy child; pregnancies can and do go wrong. When they do, the poignant responsibility of caring for grieving parents usually falls to the nursing staff. How can nurses best be prepared for this challenging task? Nurses, after all, are people with their own histories and values, and many are parents themselves. As individuals, what might influence their ability to give optimal care when parents have suffered perinatal loss? This last question was the subject of my research during the summer of 2005 at the Elliot Hospital in Manchester, New Hampshire, where I am a registered nurse in the labor and delivery unit.

### Perinatal Loss

Perinatal loss comprises those losses involving miscarriage (before twenty weeks), stillbirth (after twenty weeks), and neonatal death (live birth followed by death). The frequency of perinatal loss is high. The incidence of miscarriage ranges from 9% in women in their early twenties to 75% in women in their mid forties. Between the third trimester of pregnancy and the first week of life, nearly seven perinatal deaths occur per 1000 pregnancies. Nurses who work in the labor and delivery unit care for mothers in all these circumstances (1, 2, 3).

Parental response to perinatal loss is individual; some see this as part of life, while others experience a devastating loss of a deeply longed-for family member. Over all, the level of the mother's grief following a loss is often unrelated to the gestational age of her fetus (2). In each instance, a nurse must be able to understand the unique impact of the loss in order to provide effective emotional support as well as medical care. Hospital nurses must care not only for the mother's medical needs during the birth and afterward, but for parents' (and often the extended family's) emotional needs as well.

Appropriate and timely delivery of care can help newly bereaved parents prepare for the challenges ahead, and provide them with future coping strategies. The perinatal loss program at the Elliot Hospital was established eighteen years ago in response to these needs. Over the years, our program has evolved into a comprehensive method of caring, attending to the needs of the newly bereaved as well as providing supportive after-care.

Unlike parents of healthy newborns, newly bereaved parents are faced with making decisions regarding issues they never dreamed they would have to confront. Some parents find themselves needing to make decisions where the child involved falls on the borderline of viability, decisions such as whether to end a pregnancy which is life-threatening to the mother and/or child, or whether to take extreme measures to save a baby born extremely premature. Among the most painful decisions is whether or not to have involvement with their baby who has died. Some bereaved mothers need to hold their baby immediately after birth. Others are more tentative and ambivalent. Sensitive modeling of caring behaviors by nurses toward the baby gives bereaved parents "permission" to love and care for their baby, thus validating their loss and facilitating normal grief processes. Parents are encouraged to see, hold, and when appropriate, bathe and dress their baby.

Another decision may be about the final disposition of the baby, and whether to have a funeral or memorial service. A ritualistic grief service, although not necessary, can be beneficial; it provides the opportunity for others to see and understand the intensity of the parent's loss and to offer support. Although parents may choose to involve a funeral director for a deceased baby, our perinatal loss program established the Memory Garden, located on hospital grounds, as an option for final disposition in cases where involvement with a funeral director is not mandated by law, such as miscarriage or stillbirth. If parents choose the Memory Garden option, all the arrangements are provided by the Elliot Hospital at no cost to the parents. Services are held for parents and their guests on Memorial Day Sunday of each year.

Clearly, the effectiveness of the nursing care can have a far-reaching impact on the shape of newly bereaved parents' grief experience. Understandably, however, nurses' responses to caring for these families vary widely; many otherwise very capable nurses can feel hesitant and overwhelmed. Often, nurses are anxious that they might say the wrong thing and cause the parents more pain. Nurses can feel overwhelmed by the intense emotions of family members involved, and become fearful that they will lose control of their own emotions.

Anxiety of any kind can produce uncomfortable bodily sensations and emotions. A tendency to avoid circumstances that might otherwise place an individual in a potentially anxiety-provoking situation is known as experiential avoidance (4). Avoidance in this sense serves the function of temporarily extricating the individual from the source of distress. For labor and delivery nurses, potential encounters with the newly bereaved are inevitable. Repeated attempts to avoid perinatal loss encounters may intensify nurse apprehension and contribute to a hesitancy to care for this population. At the least, it is very likely that experiential avoidance would interfere with a nurse's ability to provide optimal care.

Researchers have recognized the sincerity of nurse apprehension. One study demonstrated that, although bereavement education for nursing staff alleviated some apprehension; after providing the care, most nurses still felt under-prepared to cope with their experiences. A helpful recommendation by another researcher was that prior to giving care, nurses should engage in an introspective evaluation in order to appreciate their own attitudes related to birth, death, and loss (5,6).

Overall, however, studies on nurses who face the challenge of perinatal loss are less extensive and probing than those done on the parents for whom they care. In particular, studies have yet to recognize the role of nurses' apprehension and anxiety toward perinatal loss, and the influence of nurses' individual attitudes and personality characteristics on their ability to provide optimal care.

## **The Study**

The purpose of this study was to provide an initial exploration of the variables contributing to nurses' experiences as they care for women experiencing perinatal loss. I used a correlational design to examine the relation between nurses' backgrounds, such as age, professional experience and religious influence, and their comfort levels in caring for bereaved parents in fourteen varying hypothetical perinatal loss situations. Continuing with the correlational design, I then explored the relation between experiential avoidance and nurses' comfort levels as they care for these parents.

Prospective participants were registered nurses at the Elliot Hospital in Manchester, New Hampshire, whose work might involve the care of women experiencing a perinatal loss in the labor and delivery setting. After being informed of the study's purpose, thirty two out of fifty nurses volunteered to participate. Participants understood that I (a colleague) would conduct the study and that their involvement was anonymous, not compensated, and had no bearing on their working record. All participants were female, age twenty-six to fifty, and had from one to thirty years of labor and delivery experience.

Participants completed a three-part questionnaire on their own time. In order to assure anonymity, participants inserted the questionnaires into sealable envelopes and placed these into a larger envelope in the nurses' lounge, which I then collected.

In Part 1, participants responded to questions regarding personal and vocational information: age, marital status, number and ages of children, personal history of perinatal loss, professional experience, political views, and religious influences. In Part 2, as a general measure of experiential avoidance, participants rated the truth [from 1 (Never True) to 7 (Always True)] of sixteen items adapted from the Action and Avoidance Questionnaire developed by Hayes et al. (4). Eight items depicted experiential avoidance conditions taken from the Questionnaire (see Table 1). Two examples are "I am able to take action on a problem even if I am uncertain what is the right thing to do" and "I often catch myself daydreaming about things I've done and what I would do differently next time." The remaining eight items, which were created specifically for this study, depicted experiential avoidance in perinatal loss conditions (see Table 2). Two examples of these questions are "I have confidence in my ability to provide competent care for mothers who experience perinatal loss in the labor and delivery setting" and "I worry that I might say or do the wrong thing to mothers experiencing a perinatal loss." In Part 3, participants rated their comfort level on a scale of 1 (Extremely Uncomfortable) to 7 (Extremely Comfortable) in caring for mothers in fourteen hypothetical bereavement scenarios with varying elements such as maternal social status, perinatal medical condition, length of pregnancy, and plans for involvement with baby after delivery (see Table 3).

## **Results and Discussion**

All data were analyzed using the Statistical Package for the Social Sciences. In order to determine the degree to which variables might be related, I conducted a correlational analysis on all possible two-way variable combinations. Variable combinations are considered significant if the probability of their relation is  $< .05$ .

All correlations involving personal and vocational items in Part 1 of the questionnaire were non-significant except for the pairing of religious influence on life decisions and comfort levels in each of the two scenarios

involving the care of a mother who has a live fetus with a known serious physical defect (numbers 2 and 10 in Table 3). These pairings revealed significant negative relations (both probabilities  $< .01$ ), that is, higher ratings on one aspect were associated with lower ratings on the paired aspect. In this case, higher ratings on the influence of religion in her life were associated with lower ratings of her comfort when caring for these mothers. Indeed, two nurses wrote spontaneous, short narratives stating they would not care for mothers in those circumstances.

Experiential avoidance scores paired with comfort levels in the hypothetical bereavement scenarios revealed five additional significant negative relations with the following scenarios: mother lives in a homeless shelter; baby is expected to deliver alive and then die (probabilities  $< .05$ ), mother plans involvement with the baby after delivery; father plans involvement with the baby after delivery; mother has a PhD (probabilities  $< .01$ ). In all significant negative relations, higher scores on avoidance were associated with lower ratings of nurse comfort. All correlations which paired scores of experiential avoidance in a perinatal loss condition (Table 2) with hypothetical perinatal loss scenarios demonstrated significant negative relations (all probabilities  $< .01$  except in the scenario in which the father persuades the mother to have no involvement with the baby, with probability  $< .05$ ). Here, higher scores on perinatal avoidance were associated with lower ratings of nurse comfort.

The significant relations between general and specific experiential avoidance (Tables 1 and 2) and the hypothetical scenarios of Table 3 are particularly relevant regarding nurse educational preparation and their ongoing support. Hayes et al. caution that experiential avoidance, although temporarily extricating the individual from the source of distress, ultimately arouses greater long-term distress through "ruminative worry" (4). Therefore, it may be ill advised to facilitate nurse avoidance by routinely assigning newly bereaved parents to more experienced and willing nurses. An alternative approach might be to offer nurses a mentoring program, incorporating hands-on supervision along with opportunities for debriefing and supportive counseling through non-threatening, post-care analysis.

Overall, nurses felt most comfortable when both the mother and father planned to have involvement with the baby after delivery and least comfortable when no involvement was planned. Here, involvement refers to parenting behaviors including, but not limited to, holding, bathing, dressing, and naming the baby. These behaviors help the parent know the baby to whom they will ultimately have to say good-bye (2, 6, 7, 8). Nurses' comfort with parental involvement may reflect perinatal loss education, where they learned that encouraging parents to have some involvement with their baby facilitates the grief process. These results convey a positive implication for the value of bereavement education: they reflect the nurse's capacity to receive, understand, and value the various helping strategies presented, and then to implement them during practical care. Moreover, as the nurse moves into the realm of proficiency, she or he will apprehend the fine distinction between encouragement and persuasion. A nurse can—and should—gently encourage parental involvement; however, in the end, it is the parents who must make the decisions regarding the degree—if any—of involvement.

Although a nurse may express discomfort or apprehension in caring for parents who experience perinatal loss, underlying such an expression is a genuine desire to provide the finest possible care. The perinatal loss nurse educator's ability to navigate sensitively through existing barriers will help ease the nurse's ability to do so.

This study is an introductory exploration into factors contributing to nurses' experience as they care for newly bereaved parents with a perinatal loss. Further research is warranted in this relatively unexplored area. For example, a broader sample base might reveal more demographic influence than did this study. Involvement of participants from other hospitals will open the study to nurses with differing experiences and educational preparation. A more in-depth analysis, exploring the lived experience of nurses caring for parents with perinatal loss, might provide a more direct insight into the phenomenology of care.

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### **Table 1: Acceptance and Action Questionnaire**

1. I am able to take action on a problem even if I am uncertain what is the right thing to do.
2. I often catch myself daydreaming about things I've done and what I would do differently next time.
3. When I feel depressed or anxious, I am unable to take care of my responsibilities.
4. I rarely worry about getting my anxieties, worries, and feelings under control.
5. I'm not afraid of my feelings.
6. When I compare myself to other people, it seems that most of them are handling their lives better than I do.
7. Anxiety is bad.
8. If I could magically remove all the painful experiences I've had in my life, I would do so.

*Note.* Adapted from Hayes et al. (2004). Participants rated the truth of each statement on a scale ranging from 1 (*Never True*) to 7 (*Always True*). Ratings on items 1, 4, 5, are reversed for scoring purposes.

### **Table 2: Acceptance and Action Questionnaire – Perinatal Loss Condition**

1. I have confidence in my ability to provide competent care for mothers who experience perinatal loss in the labor and delivery setting.
2. I worry that I might say or do the wrong thing to mothers experiencing a perinatal loss.
3. I feel anxiety-free when I care for mothers who experience a perinatal loss.
4. I feel that I can better take care of mothers with perinatal loss when I am able to control my feelings.
5. I worry that if I care for mothers with a perinatal loss, my day will be very sad, and I might cry.
6. I feel that some nurses are better equipped to care for mothers with perinatal loss than me.
7. I get upset with myself when I experience anxiety as I care for a mother who is experiencing a perinatal loss.
8. I feel that my own painful experience with perinatal loss, either personally or through a close friend or relative, has enhanced my ability to effectively care for mothers who experience a perinatal loss.

*Note.* Adapted from Hayes et al. (2004); inventory created for this study. Participants rated the truth of each statement on a scale of ranging from 1 (*Never True*) to 7 (*Always True*). Rating on items 1, 3, and 8, are reversed for scoring purposes.

### **Table 3: Hypothetical Bereavement Scenarios**

1. A mother is laboring at term. She has a known Intra-Uterine Fetal Demise (IUFD).
2. A mother's fetus has been diagnosed with Trisomy 18. She has chosen to deliver her baby at 20 weeks because of the high probability that the baby will not make it through to term, and if it does, the baby will face numerous medical problems with only a slight probability that it will live to its first birthday.
3. The mother plans to be involved (including, but not limited to, seeing, holding, bathing, dressing, naming, etc.) with the baby after delivery
4. The mother with a loss has a PhD, and teaches at a local university
5. The father tries to persuade the mother to have no involvement with the baby after delivery.
6. The mother in labor experiencing the loss is 35 years old.
7. The mother in labor experiencing a loss has two healthy children. This is her first loss.
8. The mother in labor is 18 years old.
9. The father supports and encourages the mother's involvement with the baby after delivery.
10. A mother's fetus has been diagnosed with Potter's syndrome – a condition in which the kidneys are absent. The mother has elected to induce labor at 20 weeks because the condition is incompatible with life.
11. The mother in labor with the loss has a poor obstetrical history, including four miscarriages and two mid-trimester losses. This is the first baby she has carried to term.
12. The mother plans no involvement with the baby after delivery.
13. You learn during report that the mother experiencing the loss lives in a homeless shelter.
14. A mother is laboring at term. The baby is alive and is expected to die after birth

*Note.* Nurses rated their comfort level as they would care for these mothers on a scale of 1 (*Extremely Uncomfortable*) to 7 (*Extremely Comfortable*).

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#### ***Author Bio***

***Catherine Overson*** is a non-traditional student in many ways. She earned a nursing diploma while living in England with her parents, met and married her husband there and brought him back to NH where they raised a family while she worked as a nurse. She took her first American college class at UNH-Manchester in January of 1999 "to see if I could do it." She decided to major in psychology to augment her hospital work. At Elliot Hospital she had already founded the perinatal loss program, where she was joined by a "dedicated team of nurses" who helped develop the program. This spring she will take time from her fulltime nursing work to graduate with a B.A. in Psychology. Her interests, however, are wide and "never-ending." She has already presented at two undergraduate research conferences; at the first she won first prize for her work on Plato and Freud. This April she will make two presentations at the National Conference of Undergraduate Research in Asheville, North Carolina: one on her research in perinatal loss and the other on possible relationships in the theories of Plato and Freud. Cathy plans to go on to graduate school for a career in teaching and research.

#### ***Mentor Bio***

***Gary Goldstein*** has been at UNH-Manchester for nineteen years, where he is Associate Professor of Psychology and the Chair of the Division of Social Sciences. He teaches courses in clinical and personal



*psychology and does research in educational psychology. During his years at UNHM he has mentored many students. Of this experience, he says, "I was especially impressed by Cathy's work in perinatal loss in terms of the incredible effort she made in getting the program off the ground and the inspiring work she does with individuals who have suffered these tremendous losses."*