Mothers' Perceptions of Benefits of Perinatal Loss Support Offered at a Major University Hospital

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Abstract

This qualitative research investigated the perception of mothers regarding hospital support after perinatal loss. Twelve in-depth interviews demonstrated that the mothers recalled the circumstances of the loss. Most identified the hospital's support services and made comments on aspects of hospital support as influential in grief recovery. Most interviewees considered themselves somewhat recovered from the loss.

***Journal of Perinatal Education,* 10(2), 23–30;** *preterm loss, stillbirth, neonatal death, hospital support protocol.*

Author's note: *Preterm loss* refers to the loss of a pregnancy and fetus between 20 weeks of gestation and 36 weeks of gestation; *stillbirth* refers to the birth of a dead fetus beyond 36 weeks; *neonatal death* refers to the birth of a live-term baby followed by death within the first week; *hospital support protocol* refers to any action or experience perceived by the interviewee as directed towards the support of the grieving parent.

Introduction

Many hospitals have developed grief and loss support protocols in their perinatal units. This research addressed the mothers' perceived extent of recovery and the perceived influence on that recovery by a university hospital's perinatal loss support program. During individual interviews, mothers related their stories and were asked to describe the hospital's role in their grief recovery.

Research Design

The study was qualitative. The participants were 12 women who, beyond 20 weeks gestation, experienced perinatal loss at a major university hospital. In-depth, semistructured interviews were conducted by the researcher who asked questions in four areas: self-perceived recovery from grief, recall of the hospital's support, attribution of the hospital's support to the recovery process, and specific aspects of the support that were considered to be useful. The semistructural interview is described in the accompanying box (see below).

Sampling Design and Procedure

Sampling was done as a quota sample with some stratification for the type of loss and length of time since the loss. Hospital records were used to locate 37 interview candidates, from which 12 interviewees were selected. Candidates were English-speaking. Selection was made to include a variety of loss and time-of-loss characteristics. Candidates who indicated "does not want to be contacted" in the protocol checklist were not sent invitations. The nurse in charge of the grief and loss program wrote a cover letter that was sent along with the research-

Interview Questions

Introduction

I am going to ask you some questions about the loss of your baby. Take your time in answering them and feel free to ask me to explain further if the question seems unclear. If you wish to skip a question and return to it later, we can do that. If you have no comment on a question, please say so. There are no wrong answers. Please give me your honest response. Remember that what you share with me will not be identified with you but may be used as valuable information for the study.

Questions

1. Would you tell me, first, how old you are?
2. How old were you at the time of the loss?
3. Do you have any living children?
4. Do you work outside the home?
5. Could you tell me something about the circumstances of the loss of your baby? How far along were you? What happened?
6. Can you describe for me how you recovered emotionally from the loss?
7. How recovered do you consider yourself now? What are some ways you can tell that you are recovering?
8. Are there some things that tell you that you are not yet recovered?
9. Could you tell me about the hospital—Did things that happened there seem useful to your feeling better about the loss?
10. Can you recall which things were most useful?
11. Which things were least useful?
12. If you were to tell another woman who had your experience about the kinds of things that will help her feel better, what would you say?
13. How has this interview been for you?
14. Is there anything else you would like to tell me or that you think would be important for me to know?

Closing

I am very grateful for the time you have spent with me and for the contribution you have made to the study. If you think now or in the next few days that our discussion has brought up things that need to be talked over with a doctor or nurse, please call me. If you wish a mailing of the results of the study, I would be happy to send it. Again, my sincere thanks.

er's invitation. Adequate responses were received within the first week. A consent form was given to the interviewee at the time of the interview. The study was in accordance with all Human Subjects guidelines and was reviewed and approved by the department administrator of the university hospital. Transcription of the tape-recorded interview provided the opportunity to examine responses to the planned questions, as well as any identifiable, unpredicted patterns of response.

The interview questions were tested for clarity among sample interviewees from the same demographic pool. Conditions were the interviewee's choice of a comfortable location. Nine interviewees chose their home, two chose their office, and one chose a public café. Interview questions were then read in the same order to enhance reliability.

Data Analysis

The results of the 12 interviews were recorded, including demographics of the sample, recall of the events of the loss, identification of hospital support services related to grief recovery, particular aspects of service that enhanced or obstructed grief recovery, and the self-perceived degree of recovery. Special attention was given to responses on each aspect of hospital service mentioned in the interview. These responses were then noted in the following terms: *emphatically positive*, *positive*, *negative*, or *emphatically negative*. The researcher qualified an emphatic response as one involving emotion, superlative language, body language, or voice-tone changes that emphasized the comment. A positive-only or negative-only response was qualified by the researcher as a response that was positive or negative in content, but not emphasized by accompanying signs of emotion, qualifying language, voice-tone change, or body-language change.

Results

Demographics

The sample consisted of 12 women between the ages of 30 and 44 years who had responded to the letters requesting an interview. All interviewees had experienced perinatal loss at the university hospital between 1992 and 1995. Two respondents were from 1992 losses, five from 1993, three from 1994, and two from 1995. Seven respondents had not delivered viable fetuses beyond 24 weeks. Five respondents had delivered fetuses beyond 24 weeks, with the latest losses being two of the sample who had delivered at 41 weeks of gestation.

The sample all had at least one living child at the time of the interview. Eight interviewees had subsequent children beyond the loss, and, in two months, one was expecting a second child beyond the loss. Seven of the sample had a living child at the time of the loss. Two of the sample reported full-time current employment, while five said they were working part-time. Three reported no outside employment and two were on leave of absence from employment. The entire sample was currently in a relationship with the partner who had undergone the loss with them. All resided within a 10-mile radius of the university hospital, although one was preparing to move out of the area during the week after the interview. The length of time for each interview varied from 45 minutes to one and one-half hours, depending upon the interviewee's speaking interest.

Another interviewee objected to the use of the words "cold room" in referring to the place where dead babies are kept.

Recall of the Circumstances of the Loss

After obtaining demographics information, the researcher's first interview question focused on recall of the circumstances surrounding the loss. Nine of the women had immediate recall. The one interviewee who had difficulty recalling the events of the loss had reported a total of five perinatal losses, with the most recent loss being a miscarriage two weeks prior to the interview. Another interviewee who had experienced two stillbirths (beyond 36 weeks of gestation) commented on the need to separate the circumstances of each loss but had no difficulty in doing so.

Self-perceived Recovery

The interviewees were asked to make a statement about how well they felt they had recovered from the perinatal-

loss experience. No responses of total recovery were made. Markers of recovery were identified by the interviewees as the ability to speak about the loss without crying, the infrequency of looking at the baby's pictures, the voluntary termination of therapy or support groups, and the ability to return to work and home activities. Three interviewees perceived themselves as "very" recovered, with small amounts of the grieving process still in existence. Five reported being "pretty much" recovered, with identifiable times when the grief was remembered. Four interviewees alluded to how "you never really recover." One interviewee commented that she did not really want to fully recover from the grief because she felt that she would be forgetting her lost child.

In two cases, interviewees attributed nonrecovery to the inability to have another baby. One had experienced medical problems with a subsequent child, which she felt brought back her grief over the loss. In one case, the interviewee attributed her nonrecovery to the need to remember the baby and, in the other case, the interviewee believed the recent loss of another pregnancy was the reason for nonrecovery.

Themes Related to Hospital Support

The spontaneous mention of the hospital's support in the loss experience occurred in 11 of the 12 interviews. Only one of the sample did not mention the hospital's services until asked to comment and, upon prompting, made only minor statements. Throughout the interviews, several themes emerged concerning the hospital's support in the loss experience. These themes are discussed below.

Timing of Support

Much of what women reported about their grief-recovery experiences with the hospital had a temporal theme. In many cases throughout the interviews, the timing of support or the lack of good timing appeared to be important factors in a mother's perception of an experience as positive or negative. Many interviewees talked about the staff's timely or untimely preparation of the mother for the event of the loss and the role that this timing played in the mother's feelings about the loss. The length of time allowed holding the baby was mentioned on several occasions. Some women praised the unrushed

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period of time with their baby after birth; others wished they had been given more time with their baby. An emphatically negative response regarded the protocol of taking the baby away for cleaning and, then, returning the baby to the mother bathed but without body warmth. A similar observation was also reported in a 1996 study of immediate management of loss (Radestad, Steineck, Nordin, & Sjogren).

The presence of the doctor or nurse at the delivery was another temporal issue important to the interviewees. Two emphatically negative comments related to the doctor and nurse missing the delivery. The time it took to get the news of the fetal demise from an ultrasound report and the time for the return of the autopsy report were also mentioned as painful aspects of the hospital experience. Another time-related aspect of care mentioned was the protocol of keeping pictures of the baby on file for an infinite amount of time and mailing a one-year anniversary card. Both procedures were reported as reassuring during grief recovery.

Nurturance

Nurturance appeared to be another strong theme in the interviewees' assessment of the support for perinatal-loss grief. Several very positive accounts were given of individual nurses completing nurturing tasks, such as brushing the mother's hair, holding her hand, casually conversing, and dressing and bathing the baby.

The interviewees' language used to describe the nurses reflected nurturance. Words included "gently, very gently," "sweet, understanding nurse," "people were very caring," and "the nurses were very apologetic." The nurturance that accompanied any support protocol seemed an important part of the process.

The sensitivity and support of the nursing staff were frequently mentioned. The majority of positive comments regarded individual nurses and included physical care aspects ("she brushed my hair"), proficiency ("she

explained things to me just enough"), and psychological support ("she was just a real, sweet, understanding nurse"). Two of the positive comments were about the labor and delivery staff in general ("people were very caring, they just couldn't believe this had happened to us again" and "you could see that the nurses were bonded together, experienced").

The physician's role was also frequently mentioned. One emphatically positive comment regarded a physician who was proficient and well networked in the hospital system. Another positive comment was about a physician who brought in a spouse who conducted grief counseling. These findings are supported by the work of Lemmer (1991) who studied what parents perceived as caring from doctors and nurses during perinatal bereavement.

Nonnurturing Actions

Conversely, the interviewees remembered nonnurturing actions as negative aspects of the recovery. One woman reported that the doctor said, "We can bring him back." The doctor was referring to the baby's return to the room after cleaning, but the mother interpreted these words as a chance for the baby's survival. The perceived thoughtlessness of this phrasing remained with the mother as she reflected on her loss. Another interviewee objected to the use of the words "cold room" in referring to the place where dead babies are kept. She believed that a more tactful term could be chosen for parents. A third interviewee objected to a nurse who came into the room and mistakenly asked, "What about a crib?" Another interviewee's emphatically negative comment regarded a nurse who seemed "disgusted" by the surprise delivery of the dead fetus. Emphatically negative comments regarding the physician's role included poor bedside manner and a comment perceived as thoughtless, such as being late for the delivery "due to traffic." One physician appeared to the interviewee to be incompetent in handling the circumstances of the loss. Similarly, Crowther (1995) reported that dissatisfaction with hospital information was attributed to physicians' difficulties in communicating and providing conflicting verbal reporting.

Administrative Aspects

The administrative aspects of the hospitalization—such as rooming arrangements, errors in care, and confusing information—were reported by seven of the interviewees, ranging in comments from negative to extremely negative in feeling. Confusion, understaffing on the unit, and being left alone in an exam room were conditions described with negative responses. Emphatically negative responses referred to mistakes about the sex of the baby and the condition of the baby, an unwanted autopsy, and lack of information about procedures. This observation was supported by Speraw's 1994 study, which also indicated that any administrative waiting period was troublesome to parents.

Loss Preparation

When the loss was anticipated, preparation for the perinatal loss and information about what the delivery and recovery would involve was reported among the interviewees. Most reports were emphatically positive ("knowing in advance what I was going to see was so helpful" and "it helped to know how the baby would look"). One account was emphatically negative ("I wish they had prepared me at the time of the ultrasound that this was going to look like a real baby").

Reading material given to parents experiencing perinatal loss was frequently mentioned as positive ("that book was so useful" and "they also gave us a book"). One interviewee mentioned that she was frightened by the title of the book but found the information to be very helpful.

Partner Concerns

Partner involvement was another theme of the hospital support of the loss. Seven of the interviewees spontaneously mentioned times when their partner was negatively impacted by noninclusion during the recovery process. Topics included not informing the partner of when to expect the delivery and what to expect, not involving the partner in bathing, holding or being photographed with the baby, and not including the partner in the over-

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night stay in the hospital. One interviewee mentioned that her partner wondered why he was not included in the interview. Another interviewee's partner stayed for a segment of the interview to add comments. Providing care for others—not just the mother—is acknowledged by Weinfeld (1990) who suggested a support committee that addresses the needs of couples, families, and staff involved in the grief process.

Memorialization and Celebration

A theme of memorialization and celebration was an important aspect of perinatal loss recovery. Many of the interviewees reported using a component of the hospital support—such as the photograph, certificate, quilt square, and chaplaincy referral—to plan a memorial, a baby book, or some personal kind of remembrance of the lost child. Utilizing the Perinatal Grief Scale, Lorenzen and Holzgreve (1995) found that such memorializations were useful to a variety of loss circumstances.

Interviewees mentioned that the certificate presented to parents in the hospital included the baby's footprints and, at appropriate times, a lock of the baby's hair. One interviewee pointed out that she framed the certificate and hung it in her home as a reminder of the baby's existence.

As a part of the hospital support protocol (and if the parents chose), photographs were taken of the baby and offered to the parents. Respondents frequently mentioned the pictures as aspects of the hospital's support ("I must have looked at those photos one hundred times a day for a year" and "the pictures were a nice touch, although we took our own photos" and "we appreciated the photos, but we wish they were full body" and "those photos were too clinical").

Five interviewees mentioned the hospital's suggestion for participating in a memorial quilt-square activity in order to honor their baby. One mention was emphatically positive and the interviewee expanded on the process of making the square together with her spouse and, then, "letting go" of the square to send it back to the hospital. Most interviewees commented on how the square was a nice idea and it was "good to know that I had the option."

The anniversary card sent to parents at the one-year anniversary of the loss was mentioned once in an emphatically positive way, characterized by the tears of the respondent.

Additional Hospital Support

The final theme was additional hospital support services. The hospital chaplaincy service was mentioned and comments were emphatically positive. One interviewee spoke about having her own priest called into the hospital by the hospital chaplain in order to receive the sacrament of the sick. Two people spoke about how beneficial chaplaincy was in helping to arrange funeral and memorial services for the baby. Social services were mentioned regarding the frequent offers for guidance and referral, and a visit by the social worker. Negative comments included a feeling of intrusiveness and the young age of a social worker. Support groups referred by the hospital were frequently mentioned ("we are a club no one wants to belong to . . . but when one joins, one knows it is the best place to be" and "offering the support group was nice"). The hospital protocol of a follow-up phone call was noted both as positive and as negative when it was promised but never happened.

Summary

The themes of timing of support, nurturance, verbal sensitivity, administrative aspects, loss preparation, and regard for providing support to extended family were described, as well as other hospital support services. Each appears to be important, congruent with existing literature, and in need of further research. Also, the memorialization a hospital's support protocol can begin for perinatal-loss patients should uniquely be examined in relation to grief recovery. It would be useful to survey how women who perceive themselves as somewhat recovered from perinatal loss have used such ritualizations to memorialize and celebrate the existence of the baby.

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Implications for Childbirth Educators

Childbirth and perinatal educators might utilize the results of this research in preparing families for the type

of support they might value if they were to sustain a loss. Educators might also use these results in their work with families who have experienced perinatal loss. Educators could also encourage their local hospital to provide additional support to parents during perinatal loss, where indicated, by suggesting how grief support may enhance the family's healthy bereavement. Educators who know that a family has unresolved issues about the handling of a past perinatal loss could use the information in this research to understand the family both during the time of the loss and subsequent pregnancies. In some settings, it may even be feasible to set up an extra session with a skilled facilitator during a current pregnancy to discuss resolving previous perinatal loss for parents with that history.

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Characteristics of a New Mother

Euphoric and Fatigued,
Woman of the hour
Clinging to the pain,
Bestowed and Empowered.

Nine months gestation.
Proudly worried,
Calmly anxious.
Nature, natural and societal expectations.

After a night of toiling
Your day finally came.
Your child lies beside you,
Blessed be his or her name.

Cry for happy,
Cry for hormones,
Cry for the baby
That once danced in your womb.

A lifetime awaits you.
Time passes so quickly.
Kissing away salty tears,
Saying prayers in darkness,
Asking awkwardly
For a gentle hand
To guide
This exhausting journey.

—Teresa Griffin Cascino, RN
Perinatal Instructor at the Mayo Foundation