Death of an Infant: Parental Grieving and the Failure of Social Support

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Parents undergo intense grief reactions following the death of their newborn infant, but frequently fail to receive emotional support from their family and circle of friends. Because this response from family and friends differs from what occurs with the death of an older child or adult, this study was undertaken to explore the events and personal interactions that helped or hindered the parents following their infant's death. Alternations in familial and extrafamilial relationships are described in seven families with infant deaths, and useful support mechanisms are proposed.

In this society, an infant's birth is generally viewed as a normal, happy event. Rarely do parents give more than a brief consideration to the possibility that their infant may die. Although infant mortality in the United States has declined dramatically in the last 50 years, still 10 to 20 of every 1,000 newborns die in the first few days of life. Because the death is not anticipated, parents are usually stunned and share a state of disbelief when a baby does die. Yet, among health-care professionals and society at large, there appears to be a view that parental grief following the death of a fetus or newborn infant is not as severe or prolonged as that experienced with the death of an older child. This view discounts the effects of bonding by the mother, and possibly the father, to the fetus that begin prior to birth and are further enhanced and matured by physical contact and caretaking.[1-3] The death of a previable or a liveborn viable infant produces intense parental grief, regardless of whether the parents touched or saw the infant.[4] Parental mourning is also initiated by the loss of an anticipated normal baby when a premature or malformed infant is born.[5] The grief reactions experienced by parents following the death of a newborn infant are no different from those described when experiencing the death of any other family member.[4-6]

The purpose of this paper is to report the nature and extent of the alternations in familial and extra familial relationships, and to present some suggested interventions we have found useful in supporting these couples.

Methods

Selection of Couples

A broad spectrum of racial, ethnic, and life experiences are represented by the families of infants receiving care in the Neonatal Intensive Care Unit (NICU) at Edward W. Sparrow Hospital. The following selection criteria were used in an attempt to reduce the inherent diversity in the population: age 20 to 35 years, white, middle class, college educated, no serious marital problems, and a wanted pregnancy. Of the ten couples who met these criteria over the period of one year, seven agreed to talk with us about their experiences in coping with their grief.

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Table 1. Infant Data

Infant Code	Sex	Weight (kg)	Birth Order	Survival (hours)	Cause of Death
A	F	0.8	1	500	Necrotizing entercolitis
B	M	3.1	3	4	Type 3-Renal dysplasia
C	M	2.7	1	2	Hypoplastic left heart syndrome
D	F	2.1	1	66	Hypoplastic left heart syndrome
E	M	2.4	2	12	Hypoplastic left heart syndrome
F	F	3.5	1	8	Birth asphyxia and Pulmonary hemorrhage
G	M	3.6	2	30	Birth asphyxia; Meconium pneumonitis

As normal procedures in the NICU, parents of an infant are permitted unlimited visiting hours and are encouraged to touch and handle their baby. The staff attempts to keep the couples totally appraised of their infant's status and offers them psychological support. Approximately one month after a baby's death, each couple meets with the infant's physician and discusses the autopsy findings, their mourning responses, and any questions they have concerning their infant's hospital course or care.

All infants were live born and survived from two hours to 21 days (Table 1). They received full intensive care management, including respirator support, and in each case, an autopsy was performed to determine the cause of death. None of the infants who died from a congenital defect had a family history of a similar defect.

Interviews

Interviews with the seven couples were tape recorded four to eight months after the baby's death. Two interviews were held with four of the families, while three had single interviews lasting $1^1/_2$ to 2 hours each. All interviews were conducted by the authors and were semistructured to cover the following areas: (1) the couples' view of the pregnancy, labor, and delivery; (2) the events in the NICU, particularly the death; (3) characteristics of the grief and whether there were any differences in the grief reaction between the parents; (4) responses of family and friends during the grief period; (5) the relationship between the couple and how they helped each other mourn; and (6) attitudes toward future pregnancies.

The couples' responses to the six study-area questions were collated and examined for common

views and experiences. Because of the descriptive nature of the data, no attempt was made to statistically analyze the responses. In the body of the paper, the phrase "external support system" is used to connote the couple's circle of friends and family.

Results and Discussion

Parental Grief

None of the individuals in this study had had prior experience with intense grieving. They were surprised by the depth of their feelings and, on occasion, were worried that these feelings were abnormal. There were no discernible differences in severity or length of mourning between the couples with and without a living child. All mothers and most fathers had a high degree of mourning when evaluated by the scoring system used by Kennell et al.[4]

With all couples, the men and women differed in the characteristics of their grief. The women felt the loss more acutely and tended to grieve for a longer period of time. Initially, the mothers had a strong urge to hold, cuddle, and rock their infants. Feelings of being "cheated" and frustrated in not having an infant to care for were expressed by all women. Mrs. F, when asked why she refused to be moved from the postpartum floor of the hospital following the death of her baby, replied:

> I needed to assess my feelings of resentment toward mothers who had their babies. Gail was mine, and if I couldn't have Gail, I found I didn't want any other baby. I was happy for the other mothers, but I felt cheated.

Unexpected episodes of acute sadness, with prolonged spells of intense crying and feelings of "deep ache" or void, were felt by the mothers. Each described a strong need to talk about the physical characteristics of the baby, the details of the hospital course and death, and her desires, expectations, and fantasies for the baby. None expressed anger or hostility toward the infant.

Successful adaptation by the woman to her pregnant state has been correlated with her degree of feminine identification, ego strength, and nurturance.[2] A mother poorly adapted to her pregnancy may have severe pathologic grief on the death of her baby. Besides looking for the nine pathologic mourning reactions described by Lindemann,[6] evidence was also sought for excessive feelings of guilt and maternal inadequacy as potential indicators of a poor pregnancy adaptation. None of the women in the study were judged to have pathologic grief or inadequate adaptation to the pregnancy.

Guilt is a normal part of mourning,[7] and it was a prominent component in these parents' grief, particularly when the child died as a result of a congenital anomaly. The women experienced these feelings of guilt to a greater extent than the men. This was particularly acute for the women with their first pregnancy, who questioned their reproductive and mothering adequacy. However, all the women felt some degree of responsibility for the death. These feelings generated questions such as: "What did I do during the pregnancy to cause this?" "What didn't I do?" "What should I have done differently?" "What am I being punished for?" The guilt feelings were prominently expressed by all couples in the four to six-week postdeath interviews and were still present to some extent at the time of this study. In spite of intellectual understanding of the medical reasons for the tragedy, their emotional responses included obvious self-blame and questioning of parental capacity. The men tended to resolve the question of responsiblity for the death and the subsequent guilt feelings sooner than the women, probably because of the inherent difference of biological and psychological adaptations during pregnancy. Having the opportunity to discuss the autopsy data proved to be helpful to each family in resolving the guilt feelings about the cause of death.

Immediately following the baby's death, the fathers felt that they had to be "strong" for their wives and could not break down and cry. One father related "I couldn't let loose until I saw that Sally was getting over it." All felt that they had been socialized with the view of a strong, unemotional male, so that this was not a new role for them. The fathers had touched and held their babies before death and had positive feelings toward their infants. This acknowledgement of emotional attachment is of interest, since there is

little in the literature on paternal attachment to infants. It is our experience that fathers who are physically involved with their infants in the NICU show clear evidence of attachment. This is particularly true of fathers of infants transported to the NICU from referring hospitals, as they often have the unique opportunity of handling and touching their babies before the infants' mothers.

Mr. E, whose baby died from congenital heart defect, was becoming increasingly angry about the lack of response from family and friends and the clear message that he should "forget about it." He said, "You are expected to maintain a stiff upper lip." For him, a significant step forward was giving himself "permission" to feel whatever he was feeling.

Societal Response

Striking commonalities emerged as the couples discussed their experiences. Foremost was a sense of extreme isolation felt by the parents. The baby's death was treated differently by friends and family than the death of an older child or adult. Typical responses received from the family and friends were: "You're young—you can always have another one." "It was only a baby whom you didn't know." "It's worse to lose a child you know."

Mr. and Mrs. G, whose baby died 30 hours after birth, were surrounded by many attentive family members and friends during the pregnancy; one friend called Mrs. G every day. However, after the death these people never mentioned the baby, and the telephone calls and visits stopped. Mrs. G responded, "Everybody acted as though I never had a baby."

Feelings of disappointment, resentment, and anger were generated by these comments. In the early phases of mourning, each couple expressed a need to talk about the events surrounding the baby's death and their feelings of grief. At the same time, friends and family steadfastly avoided mentioning the infant or the death. For three couples, no evidence of sympathy or condolences were received from people considered close friends. Each father related that no one at his place of employment commented about the infant's death or acted as if anything had occurred. Two mothers had the similar experience of receiving a telephone call from a friend, and having the friend hang up after the conversation without commenting on the death after having been told of it.

The conspiracy of silence concerning the death manifested by family and friends, seemingly to protect the parents, actually produced severe distress for each couple. Their immediate distress was a sense of isolation. The external expectations were that the couple would not grieve and would "put the death behind them and get on with life." Each couple soon came to realize that the baby was viewed as replaceable by the external system and that they should disregard their feelings of attachment. When asked why their family and friends failed to respond to their grief, the couples offered the following replies: "They're afraid to talk about death." "They think they are protecting us from pain by not mentioning the baby." "They're afraid of their own emotional response and may break down." "They just don't understand us." "We scare them when we talk about it." In all cases, the couples began to feel that they were behaving inappropriately because they were grieving, rather than realizing that it was the external system that was inappropriate. With no acknowledgement of the infant's existence, keeping the baby real became a major task. Most parents wished they had had a picture of their baby to affirm to themselves that the child had existed.

Possibly, family and friends of the couples in the study viewed the infant as an "it" rather than an individual with a human identity. Such a conclusion could explain the comments made to the parents. Individuals of the expected external support system did not have the opportunity to attach to the baby and usually had no feelings toward the infant. If the attachment to the infant is not recognized, then parental grief may be viewed as merely mourning the loss of the "expected personality" and a potential source of gratification. Empathy for that type of loss will be brief, and extensive grieving will seem inappropriate to family and friends. Although other reasons for the lack of empathy and support for obviously grieving and pained individuals may exist, they were not apparent from our interviews. Each couple commented that they had considered their relationships with their parents and other family members to be good prior to the death of the baby.

Engel has pointed out that grieving individuals need the opportunity to verbalize their feelings.[7] The couples in this study sent out clear cries for help but received no response from their expected external support systems. There was little evidence of families gathering together and sharing a mutual loss except possibly at the time of the funeral. We wondered whether there might be a delay or interference in the resolution of grief in these parents when the social system denied them the opportunity to express their feelings and experiences. The question cannot be answered fully in this study because each of the individuals turned to his or her spouse for support and did not attempt to resolve the grief alone. However, it is clear that the lack of support made this period of grieving more difficult for the individuals involved.

Resolution of Grief

During the course of the interviews, the couples either resolved or were close to resolving their acute grief. The acute grief period lasted from six months to one year. In this study, sharing of feelings between the partners and the resulting mutual trust proved to be the most important factor in the resolution of the parents' grief. Kennell and Klaus had noted with their study families the frequent occurrence of a disturbance in communication between the parents following the death of an infant.[8] From our interviews, it is possible to conceptualize how a lack of communication comes into being. The pace of the resolution of grief was clearly different for the partners, with the father progressing much faster in the process. All the fathers returned to work soon after the death and had an eight to ten-hour period each day in which they were distracted from thinking of the death. In addition, the father did not have the same degree of biological and psychological attachment to the infant that was present in the mother, and thus had less intense grieving. In time, the couple became aware of the difference in the grieving pattern between themselves, which produced frustration for both partners. The man's frustration grew out of his inability to aid his wife in resolving her feelings of sadness and acute grief, and in finding little support from his wife for his own feelings. Coming home each day after work to a crying, grieving wife proved to be a tremendous problem for each of the men. The women, home alone and without anyone to share their feelings, unloaded their anguish on the only one they felt understood and would listen to them. They found it difficult to understand why their husbands were not feeling the grief as intensely as they themselves. For the couples this was a critical point in their relationship as they learned that they had to express their feelings and frustrations. It was at this point that they also realized that family and friends were unavailable for this task and that their marriages would be in jeopardy if together they did not resolve their grief. Once the lines of communication were fully opened, the process of resolving the grief seemed to occur in a slow but definite progression over a four to six-month period of time. It was of interest that, following the improvement in communication, the couples also tended to resolve prior, unsettled conflicts. For all seven couples, the relationship between the partners was felt to have deepened and improved because of the death, and five couples actually came to view the death as an opportunity for growth in their lives. Besides gaining new understanding of each other, the couples also made definite changes in their life-styles and values. The concept of friendship gained new meanings and commitments for these couples. One couple came to define a friend as someone with whom they felt free to cry and share their feelings. Those couples with living children felt that they had come to appreciate and love their children in new and improved ways. All these changes occurred in marriages that were described as stable, happy, and satisfying before the baby's death.

Summary and Recommendations

Seven couples, selected from a segment of a population that is viewed as possessing the advantages of this society, encountered significant problems in resolving their grief following the death of their baby. Society failed to support them at this critical moment, and they were forced to experience the mourning process in relative isolation.

Currently, there is only anecdotal evidence on the grief and support systems for families from different racial and social strata, and, thus, it is not possible to draw broad conclusions or implications on parental grief. This study does suggest that our society is not supporting adequately these parents and that society's view of the perceived worth of a newborn infant may have changed over time.

The following recommendations are based on information derived from this study, plus experience gained over time in working with grieving parents. Each practice has been incorporated into our approach to families after it was found to be a useful modality.

1. Health-care providers, working in the areas of prenatal, delivery, or postnatal care, need to be taught the dynamics of the grief process, particularly of parents, and be comfortable in encouraging the couple to verbalize their feelings and grieve openly. We use conference sessions and videotapes, made with grieving couples, to teach this material.

2. If an infant is likely to die or is actually dying, the parents should be allowed and encouraged to see and touch their baby. Clearly, there are situations, such as an infant with anencephaly, where exceptions are made to this approach. We have found that taking an "instant" picture of the dying infant and giving it to the parents was extremely useful to them during the process of mourning.

3. The stages of the grief process should be discussed with the couple once they are over the initial outpouring grief, so that they are aware of the wide range of emotions that can occur. This is also a good time to encourage them to verbalize their feelings.

4. Prior to discharge of the mother from the hospital, a time should be scheduled for the couple to visit with the providers to talk about what they have experienced since the baby's death. We schedule this visit seven to ten days from the infant's death with the understanding that they can call or see us at any time. These visits are used both to monitor the grief reactions and to encourage the couple to verbalize their feelings. At this time, we discuss the potential responses they may encounter from friends and family.

5. At approximately four to six weeks following the death (or when the data are available), the couple is seen to discuss the autopsy findings and to answer any questions they may have on the pregnancy, labor, delivery, or the care the infant was given. Having the data from an autopsy is extremely helpful in aiding the parents to resolve their feelings of guilt and to facilitate their understanding of the cause of death (if known) and of genetic implications, if any, for future pregnancies.

6. Visits should then be scheduled according to the desires of the couple for continued support. In our experience, by four to five months postdeath, the couple is seeking opinions on the advisability of having another child. When this question arises, we discuss with them the emotional problems and difficulty of detaching from a loved one and at the same time, attaching to a new love object. Our only advice in this area is that, if they desire another child, they should wait until the acute phases of the grief process are over, so as not to view the future infant as a replacement for the lost baby.

7. Early in the mourning process, we ask the couple if they would like to talk with another couple who has experienced the loss of a baby and successfully resolved their acute grief. If they are interested, we facilitate such a meeting with one of the families who have worked with us in the support program.

8. At all decision points in this process, we encourage the couple to select the alternative they desire, not the one family or friends feel they should take. Performing an autopsy, funeral arrangements, and future pregnancies are examples of such decision points.

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