The Family Physician's Role Following a Neonatal Death

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The process of grieving for the death of a neonate is different from other grief processes. The family physician is in the unique position of playing a significant role in assisting families who are living through this tragedy. Even if the family physician has not been part of the prenatal care and delivery, he or she will continue to see the parents for weeks, months, and even years, long after most other support is gone. This paper outlines seven possible specified times when a family physician can intervene in aiding the couple through the evolving grief process.

As the findings of researchers suggest, and the words of the parents themselves confirm, "keeping a stiff upper lip" is a destructive waste of time. The object is not to forget, but to remember . . . and go on.

—Nancy Berezin[1]

Neonatal death provides the family physician with a unique opportunity to help grieving families. The cause of the death, be it perinatal or intrauterine, is irrelevant to this article. The concern here is with the characteristics that are specific to this loss. Fathers, mothers, and siblings react differently to a neonatal death. This article offers suggestions that may be useful to the family physician regardless of the level of involvement in the pregnancy and delivery.

Substantial differences distinguish the impact of a neonatal death from that of the death of an older child or adult. First, there are few memories associated with a baby who is either born dead or dies shortly after its birth. Often, no one other than the parents has seen, held, or known the infant who dies so early. No bonding has developed between this child and the relatives and friends who will make up the mourners. In contrast, the persons grieving for the death of an older child or adult grieve for a known and beloved person for whom these relatives and friends have shared memories. In neonatal death often only the mother and the father have known their child as an individual being; therefore, they have no one with whom to share this loss.

Second, parents and siblings have been awaiting the arrival of the new family member from the moment the pregnancy was confirmed. After months of growing anticipation and preparation, emptiness is the only outcome.[2] Friends and family have not developed this same sense of anticipation.

The mother of the neonate has specific issues with which she must deal. Her breasts are engorged and prepared to feed an infant. She is postpartum. Her abdominal muscles are soft. She may have a painful perineum. These circumstances usually would not trouble the new mother of a healthy child. With infant death, however, the mother has to deal with the constant reminder that after months of physical change, she has nothing to bring home but an altered and not altogether friendly body.

A third set of problems arises when friends and relatives try to deal with the neonatal death. Frequently the parents will hear various unsatisfactory clichés. Examples of such inadequate attempts at comfort are, "This is God's will," "You're very young, you can have another," or "You already have a healthy child, you should be grateful for that." Least useful is, "Why do you feel so bad? You didn't even know this baby."[3]

There is no predictable "normal" time at which the grief should have worked itself through. People mistakenly tend to believe the grieving process should be completed by 6 months, after which it is not uncommon for the parents to

Submitted, revised, February 14, 1989.

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hear, "Your grieving should be done. Pull yourself together." The parents will begin to wonder whether they are abnormal. Friends and family will have grown weary of a grieving process that has not involved them, and this may further isolate the parents. At this time grieving parents often seek support groups or counseling.[4]

TYPES OF GRIEF REACTIONS

The family physician should be cognizant of some of the specific grief reactions that are seen with neonatal death.

Shock

For some bereaved parents, shock is the dominant first reaction. These individuals are not in a normal healthy state. Take care, as with any other situation of grieving, not to judge prematurely that the parents have regained their normal equilibrium.

Disorganization

Mothers grieving for a neonatal death often admit that they do not have the emotional energy to care adequately for the other children. They may be unable to help these children with their own responses to an infant sibling's death. The father's disorganization may not be so obvious. It may be reflected in his work performance. Sometimes the couple may make precipitate decisions, such as a geographical move or job change.[5]

Anger

As with any other grieving process, there will be anger. The family physician may receive the brunt of misdirected rage, and should be aware that this displacement is not intentional. The parents may manifest their anger with God. Whether the parents will utilize their prior religious experience as a useful means of helping cope with the death cannot be predicted. The parents, unable to understand why a just God would be so unfair, may completely reject all previous religious commitments, or they may espouse a new religious bond as a direct response to the tragedy.[5]

The woman who is postpartum may be angry with her body. With engorged breasts, vaginal bleeding, and feeling fat, she may behave irrationally in an attempt to deny the recent pregnancy. She may use tampons before she should. She may feel the need to stuff herself into any sort of nonmaternity clothing. Her body tells her she should have a baby. She tries to tell her body it is not true.

The parents may express anger toward one another, which can be the first indication of future problems. Most destructive is the anger that is turned inward—the anger the parent directs at him or herself. This anger is associated with the familiar question, "Why me?" Learning the reason for the death becomes paramount in the couple's minds. They manifest a great need to know why. Often there is no answer.[6]

Loneliness

As noted earlier, friends and families may not be so supportive or comprehend the magnitude of the parents' grief for a neonatal death, isolating the couple in their grief. Furthermore, men and women in Western societies tend to grieve in very different ways. Women often will want to talk, to cry, and to go back over the experience again and again. In contrast, men may not want to discuss their feelings. These differences can create problems between the partners, disabling them as a support system for one another.[7,8]

Such incongruent grieving may lead to serious problems within the marriage. Sex, so often a bond of love, can become a problem. Sexual intercourse resurrects concerns about conception. The parents may not want to conceive, or may be very ambivalent about conceiving another child at this time. The pleasure, joy, and intimate friendship usually associated with the love act can bring a burden of confusion. As a result, love and sex may not be an effective solace in this situation.[8] If the marriage was shaky before the tragedy, it may not survive this event. On the other hand, couples who successfully overcome the problems of the death often establish an even stronger relationship.[7]

THE FAMILY PHYSICIAN'S ROLE

Before trying to assist the parents who are grieving for a neonatal death, the family physician should examine his or her own reactions to this unique grief process. As the physician reviews the components of grief, some difficulties can be anticipated. As noted earlier, the parent's anger may be directed, entirely and irrationally, at the physician. To handle this anger, the physician should have a plan that is not destructive to either himself or to the supportive relationship with the patients.

The explicit skills essential to dealing with neonatal death are not uniformly addressed in a family medicine residency programs. The following is a list of suggestions and considerations for the primary care provider.

At the Time a Problem Is Recognized

Be Candid, Be Honest. If an unfortunate outcome of pregnancy is anticipated, meet with the parents together, if at all possible, when informing them. Telling either parent without the other about the impending death of the newborn places an enormous burden upon that individual. If the death occurs unexpectedly during delivery, inform both parents immediately and simultaneously.[9]

Discuss Decisions Together. Any decisions about interventions should be made together and they should be made without moral judgments. The physician's role is to provide the information, to clarify the options, if any, and to help guide the parents in making a wise decision for their own future and that of the child in question.

Suggest Parents Hold the Baby. If the neonate is living and is expected to die soon, suggest that the parents hold and love the infant while it is still alive. The physician should use discretion in encouraging the parents to see or hold a deformed baby, keeping in mind that the grossest of physical deformities can usually be covered with blankets. If there is no hope that this child can be saved, give the parents the option of having the baby stay with them around the clock. Photographs taken now will prove helpful later in the grieving process.

Point Out Importance of Naming the Infant. Encourage the parents to name the baby if they have not already done so. A name provides the baby with an even clearer identity to which the parents may attach the grieving process.[9]

Include Siblings and Grandparents. Siblings, grandparents, and close friends should be urged to visit if at all possible during this time. They should also be encouraged to see and touch the baby. By doing so, these individuals will be helped to accept that there has been a living, breathing, human being. It will aid them in their own grief and will make them more effective in helping the parents through the succeeding grief period.

Urge Vaginal Delivery, if Possible. If the infant is known to have died in utero, explain carefully to the parents why it is important that the woman have a vaginal delivery rather than a cesarean section. To put a woman through the distress of labor knowing she will have a nonviable child may seem unusually cruel; however the mother will benefit by seeing her baby and then leaving the hospital relatively promptly. During the course of the labor she should have as much pain control as is necessary, but she should not be so sedated that she does not experience the birth or have the opportunity to hold her baby. Following vaginal delivery, she should be feeling well enough to participate in planning for and to attend her infant's funeral.

Keep the Family Together. If the critically ill neonate must be transferred to another institution for care, the mother should be discharged with the baby. In this way the entire family, mother, father, and endangered infant, may stay together. If the parents are separated, an undue burden rests on the father to be the emissary bringing news, both good and poor, to his partner. He also becomes responsible for making decisions on the infant's behalf.

At the Time of the Death

Let Parents See and Hold Baby. If the parents have not been able to handle the child before its death, provide the opportunity for them to hold and see their baby for as long as they feel the need.

Give Mementos. Provide the parents with the option to leave the hospital with mementos—any identification bracelets, photographs, footprints, blankets, head covering—that have belonged to their baby. If the parents are reluctant to take such items, an effort should be made to keep the mementos available. Experience has shown that frequently the parents will ask for these reminders later as their grieving progresses.[9]

Limit Sedating. Medicate the mother only as much as is necessary for pain during the time immediately surrounding the infant's death. Do not sedate her to the point that she is unaware, for she should be allowed to see and feel and grieve.[5]

Do Not Offer Clichés of False Comfort. In talking with the parents about the death of their child, do not use the previously mentioned clichés. Find out how the couple feels about the situation before making any assumptions. If a message of condolence is required, "I'm sorry" is a good start. A hug, a kiss, or taking the hand—anything that can be done to show personal emotion—is much appreciated.[9]

Address Both Emotional and Physical Needs. Deal with both the emotional and the physical needs of the parents at this critical time. Discharge the mother as quickly as possible. Any follow-up care is better done in her own home by the physician or a visiting nurse. If the mother's physical condition requires that she remain in the hospital after the infant's death, give her a private room on the obstetric floor. She should not be in a room with another mother who has a healthy baby. Transferring the grieving postpartum mother to another unit may spare her from observing

happy parents, but she will find herself isolated from those caretakers who best understand neonatal loss. Therefore, try to keep her where she may be visited and cared for by obstetric and postpartum nurses who are familiar with this particular grief.

Explain Cause of Death. Answer as clearly and as fully as possible any questions the parents have. They will want to know why their baby died. If the answer is available, tell the truth. If it is not, provide the parents with a reasonable theory. Strongly advise the parents to give autopsy consent in an attempt to determine why the infant died.[10]

Before Discharge From the Hospital

Discuss the Funeral. The parents should be encouraged to have a memorial service. The funeral should be delayed until the mother is sufficiently well to attend it. The parents should specify the extent of the service and the individuals whom they want to attend. Generally a funeral for a neonate or for a stillborn infant is much simpler and costs a great deal less money than other funerals. It is important that there be a final ceremonial conclusion to this child's brief life so that the parents may proceed to grieve.[9,10]

Explain Mother's Physical Restrictions. Answer all questions regarding physical restrictions for the mother's health and her recovery from the postpartum period. Make sure that instructions are clear and succinct and that they attend to her physical needs. Mention sex now to open a dialogue with the parents about the resumption of normal sexual activity. This openness will permit questions about the decision to attempt another pregnancy later.

Advise Parents on Informing Others. Counsel the parents to choose one person to be responsible for making the death known to friends, relatives, and co-workers. Suggest that when the parents meet someone who does not know about the death, they open the conversation with, "You had no way of knowing, but . . . " and thus avert queries and embarrassment.

Address Sibling Reactions. Careful attention must be paid to sibling reactions to the neonatal death. In dealing with a toddler, the parents must be careful how they describe the death of the baby. For example, do not use the euphemism "the baby simply went to sleep." The sibling may then fear falling to sleep. If one uses the term *sick* to describe the baby who will never come home, it is imperative that this sickness be carefully defined. The sibling must understand that the fatal sickness has no relationship to this child's own colds and coughs. Also remind the parents that they must be aware of the possibility of guilt in the siblings. A child who has anticipated the baby as invading his or her home may have had fantasies that the child would never arrive. When the new baby does not come, the child, thinking that secret wishes may have caused the baby's death, can become frightened. Certainly the child with an emotional development of greater than 6 years of age should be a part of the funeral services and be actively included in the overt actions of the grieving process.[4,5,10,11]

At Three to Four Weeks Postpartum

Call the Parents. At this time the family physician should telephone the parents. It is very important that they know the physician is still thinking about them and checking on their progess.[6] There could be value in a home visit at this time, also.

At Six Weeks Postpartum

Assess Individual and Family Progress. At the 6-week visit, in addition to the routine physical checkups indicated, share preliminary autopsy data. Both parents should be present for this visit. If possible, ascertain where each parent is in the grieving process, and assess the progress the family is making. Even at 6 weeks the direction of the grief can be changing. The parents may be becoming increasingly supportive to one another, or they may be growing apart. There may be difficulty with the children, problems sleeping, or feelings about their own guilt and anger. Ask about these issues and listen to what the parents say.

Suggest Support Groups. Suggest support groups at this time. The physician should learn what is available in the parents' particular area.[8] SIDS and Compassionate Friends, are examples of support groups, though they generally deal with the deaths of older children or infants who have been in the home for some time. If there are no neonatal support groups in the immediate area, try to put the grieving parents in touch with men and women who have had the same personal loss.

Discuss Future Pregnancies. The 6-week visit is probably a good time to begin talking about concerns for future pregnancy. Although 6 weeks postpartum may not be the optimal time to plan for another child, the question usually has surfaced in the patients's minds. Advise them not to make any major decisions regarding another pregnancy at this time, as it is too early in the grieving process. At the same time discourage the couple from taking any perma-

nent steps that might impair future decisions about pregnancy. The waiting period before the parents are able to make cogent decisions about the next pregnancy is highly variable. If there are concerns about parental age or potential infertility, these considerations may prompt the physician to encourage the patients to make the decision early. Give them all the time they need so a new pregnancy does not represent a substitution for the prior loss. A new child will not replace the dead child, and a new baby will not make the parents forget that there has been a baby before. Their grief work must have progressed to where they can accept a new pregnancy in its own right and yet have consolidated the necessary memories about the dead infant.[2] Remind the parents that the next pregnancy, should they decide to have one, is going to be very different from the last experience. It will be fraught with concerns and fears that were probably not present before. The parents need to consider these differences as they decide whether and when to attempt another pregnancy.

At 6 Months

Share Final Autopsy Results. Share any final autopsy reports or further data explaining the death of the infant.

Reiterate Expectation of Continued Grieving. Reiterate and reassure the parents that it is normal to still be grieving, that there is no time limit to grieving. Remind the parents that the first major event within the year after the child's death is going to be significant. Inform the parents that they can expect, and are not to be alarmed by, a resurgence of their mourning at such times as Mother's Day, Father's Day, Christmas, and particularly the upcoming birthdate or anniversary of the deceased infant.

Anticipate Possible Loss of Support for Parents. As the grieving parents move into the second 6 months, the support others have provided may diminish or cease. It is important that the parents maintain one or two people with whom they can continue to discuss their grief. Encourage the mother and father to be patient with one another, since they may not be coping in similar ways.[8]

Ask About Siblings. Inquire about the mood, state of mind, and functioning of other members of the family, particularly other children.

Ascertain Need for Referral. There are a few families who progress to pathological grief and require a referral for extended therapy. For example, a person with continuous and progressive inability to function at work or home should be evaluated. Depression may develop.

Before the First Anniversary

Discuss Upcoming Anniversary. Discuss openly with the parents the upcoming anniversary as it approaches. Point out to them that the anticipation of the anniversary and the reliving of the birth and death is usually worse than the actual day.

Discuss Future Pregnancies. It is time to discuss again future pregnancy. By this time the parents have probably made a decision. They may have decided against another pregnancy. This decision is not an abnormal response to their grief. Support them in their choice. Remind them they have the option to change their minds at a later date. If the parents have decided that they wish to proceed now to another pregnancy, they need to know their physician will be with them to help in any way possible.

SUMMARY

The family physician will continue to have an ongoing physician-patient relationship with the parents who have lost a newborn. This long-term contact is unique. This paper has outlined a number of social, psychological, and medical approaches that can be used by the physician. The physician needs to be attentive to the short-term needs of the parents as well as to recognize that the process continues over an extended period. These suggestions, coupled with the family physician's empathic skills, will aid the parents in grieving successfully.

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