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Medical Care
The Families’ Needs and Experiences

Death in obstetrics just does not seem to fit. Doctors enter the field to help create life. The nurses want to work in maternity so they can rejoice with the parents of new babies and enjoy the contact with cuddly newborns. Few people are prepared to deal with death and bereavement in such a setting.

It is easier to ignore death than to confront it, easier to act as if nothing has happened and send the parents home quickly with little or no explanation, support, or encouragement. Dr. S. Bourne of London agrees. When he surveyed the physicians who had presided at one hundred stillbirths and one hundred live births, he found that

the doctor whose patient has had a stillbirth does not want to know, he does not want to notice and he does not want to remember anything about it. This must mean doctors under strain and a group of patients in danger of neglect.

This attitude can be found not only among physicians but other hospital personnel as well. It may seem callous but it is usually due to the staff’s lack of understanding and feelings of inadequacy in helping the bereaved parents.

Hospital staff members are the first people present when a death occurs. It is in their power, through their reactions and the quality of care they provide, to make an enormous difference in the experience of the parents. The staff can help make the
tragedy more bearable and avoid making it worse by insensitivity, error, or inattention to need.

In far too many hospitals, staff members are untrained in ways of helping parents. They restrict contact between family and baby, dispose quickly of the infant who has died, unthinkingly place a bereaved mother in a room with the mother of a healthy new baby, and generally ignore the needs of the distraught couple. These hospitals have either not established policies for responding to tragic birth events or they fall back on restrictive policies that make the experience even more traumatic.

In some hospitals, the staff is trained to meet the special needs of bereaved parents. In these cases the parents benefit greatly, as does the staff, by having something to offer. What the staff can offer that parents appreciate most is a completeness of information and an understanding of the parents' emotional needs. When doctors and nurses meet these needs, with or without a conscious policy, parents remember them gratefully as "terrific, sympathetic, just like family."

Many parents, however, do not benefit from a prepared hospital staff. Sometimes, especially with a miscarriage, the hospital stay is very brief, or they do not go to the hospital at all.

The responsibility of medical personnel, however, begins early in the pregnancy and extends to follow-up visits. It is during these outpatient visits to the doctor and in preparation classes that parents can begin to air their fears and gather the information that will help them if problems develop.

Expectant couples often do not want to know that it is possible for something to go wrong. "It won't happen to me," they reassure themselves, blocking out any hints that not all pregnancies are successful. For many, "doctor knows best" and parents prefer not to raise questions; if they just trust the physician completely, then everything will be all right. Some physicians encourage this attitude and frown on patients who ask questions, even belittling their worries. Yet even when a physician or childbirth educator responds to all the fears and explains the possibility of problems, some parents may not pay attention or will become annoyed at being alarmed.

If these parents do face a complication, they are completely shocked and unprepared. Although no amount of advance information can fully equip a person at the time of tragedy and too much warning can create unnecessary anxiety, many parents wish afterward that they had had some idea of what to expect and what they had the right to ask for. Physicians and childbirth educators can provide this for parents—the reassurance that in all likelihood their baby will be fine and the knowledge that if he or she dies or is very ill they should have time with the baby and call upon people who will be able to help.

Some physicians believe it important to tell newly pregnant women at least about the possibility of miscarriage, since it is so common, and advise them what to do in case they have some spotting. Women who discover they are bleeding are therefore not taken totally by surprise.

During prenatal visits, doctors also discuss genetic tests with those women for whom it may be appropriate. If a deformity is found, the physician can help tremendously in deciding whether to abort and in explaining to parents what an abortion is like. Too often parents go through this experience with very little support from medical people.

When doctors and nurses are unprepared and frightened to approach someone who is distraught, a parent may interpret their response as a sign that he or she is an outcast, someone terrible to be ignored and isolated. As one mother of a stillborn boy recounted:

"I felt my doctor had deserted me. He never called or came to look and see how I was doing. I called his office and it was days before he even returned my call. Didn't he even care?"

In a study of middle-class parents whose babies were stillborn, sixty percent expressed dissatisfaction with their physicians, finding them unsupportive, uncaring. In our own interviews, two-thirds cited dissatisfaction with some aspect of the care they received. This does not mean the doctors do not care, but many do not show their feelings. Many agonize over whether they could have done something to prevent the tragedy. They are uncomfortable with death and with the necessity of facing a
family they feel they have failed. So, feeling inadequate and, at the same time, being wary of the parents’ emotions, a doctor may try to avoid the situation altogether. As Dr. Abraham Bergman writes, “Our ethos is cure rather than care, and death, after all, represents failure. We quickly turn back to tasks where the tools we possess can be applied.”

In many cases, there is no physician whom parents know and to whom they can turn for help. The many poor women who rely on public hospitals or clinics often see a different physician or resident on every visit and several unknown medical students and doctors when they enter the hospital. Many middle-class women have a physician who is part of a group and who may not be present when they deliver. This situation can be particularly hard, as one woman felt when her baby died a few hours after birth:

I went into labor on a weekend and my doctor was out of town. His partner was called in and was there during the crisis. But I had only met him once and never liked him very much. That just made everything harder on us when we needed someone who knew us to talk to.

In some settings, the nurse-midwife is playing an increasingly important role in assuring continuity of care. In large group practices or clinics, a mother can feel more secure knowing that there is this one knowledgeable person whom she will see at every stage of pregnancy and delivery. Many parents are more comfortable with the midwife; they feel she is less hurried and more sympathetic and responsive to their questions.

What parents want most from the medical staff is information. A father whose son died shortly after birth complained about how difficult it was to obtain an explanation:

I needed to talk to the doctor, to find out what happened. But I never really got any answers. I didn’t expect to know every last technical detail, but at least some explanation so we could make sense of it and figure out where to go from there. Had we done something to cause this? Should we have another baby? But the more we asked, the more defensive he seemed, as if we were accusing him of having done something wrong. All we wanted was to know, not to blame him.

Since anger is common after a death and malpractice suits are becoming more prevalent, a doctor may interpret persistent questioning as an attack. Sometimes it is. But the physician who avoids all questions succeeds only in promoting mistrust and suspicion. The physician who can accept anger as a normal reaction, who makes direct, honest, and immediate statements about what is happening, “without any word games” as one father noted, without trying to “protect” parents from harsh reality, is the most appreciated.

Providing an explanation is not a simple task. Sometimes there is none. And even if there is, at a time of shock people cannot assimilate a great deal of technical information; they may hear only part of the explanation or misunderstand it. For example, two people may hear very different messages in the same statement. One mother whose child was born with grave deformities requiring medical intervention mentioned this problem:

It is interesting that through the whole process my husband and I read everything differently in what the doctor said. My husband would pick up all the negative facts and made his decision not to treat the baby very quickly, and I would hold on to a positive fact and wouldn’t give up so fast.

To counteract these difficulties, it is usually necessary for the doctor to explain what has happened several times and to be available for questions that may arise later. He or she may also ask the parents to feed back what they have heard in order to know how much they have understood. Parents at first may focus on one aspect of the experience; later they will begin to wonder about another aspect. The physician cannot completely answer all their questions in a single session shortly after the event. For this reason, some doctors meet several times with couples during the weeks following their loss. Some write down important facts and instructions so that parents can review them in a less hurried setting.

Even before parents leave the hospital, there are many ways
in which an aware and sensitive medical staff can help them. Perhaps most important is encouraging the parents to see and hold their baby. This opportunity, even after a late miscarriage, is being advocated increasingly by nurses and physicians. They are responding to studies reflecting the damage caused by not seeing the baby and parents’ comments, such as: “If only I could have seen her. I have nothing to hold on to, nothing at all” and “I still remember what he looked like, a perfect baby. I treasure that image in my mind.”

Too often a physician may feel that the father’s viewing of the baby is sufficient. But the mother needs the opportunity just as much. Members of a medical staff are especially reluctant to show parents a badly deformed infant or one who has been dead for a time before birth for fear that parents will be emotionally harmed by this sight.

Nancy O’Donohue is one of the growing number of people who feel differently. As nursing supervisor at Kings County Hospital in Brooklyn, she became convinced from her own experience with over four hundred families that seeing the baby is best:

We never once had a mother who saw her baby that was deformed and regretted it. I have seen a mother who had a stillborn baby that was perfectly formed but chose not to see him and then came back later wanting to know if he was human.

We always describe what the baby looks like. Sometimes if the baby is very severely deformed and even the nurses can’t bear to see it, we still offer the mother the possibility of seeing the baby but secretly hope she’ll say no. Many do accept the offer, and the result is always positive. In one case, for instance, the mother said, “I want to see him anyway.” A month later, when she was asked what the baby looked like, she talked about his perfect ears—parents always find some positive aspect to focus on.

Initially, parents may refuse to see an infant but regret this decision the next day. They may think it is too late to change their minds or be afraid to ask. For these reasons, O’Donohue gives the parents a second opportunity after they have had a chance to think about their decision. She has even retrieved infants from the morgue and wrapped them in warm blankets to show them to the parents.

In a growing number of hospitals, a staff member takes pictures which are available to parents. Some decline at first but return weeks later asking for the photo. Photographs are especially helpful to the parent who never saw the baby but later seeks reassurance that he or she was real and not a monster. For some people a picture is not only a cherished memento but also tangible evidence to others that there really was a baby.

The pictures should be taken soon after the delivery or death, with the baby dressed and presented to look as good as possible. Because seeing the photograph for the first time can be painful, it is important to give it to the parents in a supportive environment. Unusual features of the baby can be explained first, so that the parent who never saw his or her infant will not be shocked by anomalies or physical changes.

When the family lives at a great distance from the hospital, the pictures may have to be sent by mail. A phone call before the photos are mailed can help prepare the parents. Sister Jane Marie Lamb of the SHARE support organization suggests that a warning on the envelope would be helpful, alerting the parents that they may not want to open the package if they’re alone.

If the baby is alive at birth and moved to an intensive care unit, the staff can provide other important services. They can allow parents not only to see their baby but to participate actively in the infant’s care. One way is for the mother to breast-feed the infant, even with a breast pump. The possibility of calling or visiting at any time and having easy access to information about the baby makes the parents feel more comfortable in the nursery. Some parents may want to stay close to their baby, and they can do so in these hospitals that provide a special room near the nursery in which parents can sleep. A tour of the unit and an explanation of all its equipment will help prevent misconceptions about what is happening. One mother regretted that no one did this for her:

There are things that happen that, if they were explained, would ease a lot of pain. For example, I thought the baby was having a
difficult time breathing on the respirator; that every breath was an effort for him. When I mentioned this later, I was told that the baby was not working hard, that it was the respirator that was working to force the air into him.

In some hospitals, when an infant is dying, the physician encourages the parents’ relatives and friends to visit the baby. This opportunity helps the parents later in their grief, because the child has been established as a real person to those around them.

If the baby must be transferred to a different hospital, it is especially important to involve the parents. Dr. Gary Benfield and his associates at the Children’s Hospital in Akron, Ohio, to which many infants are brought from other hospitals, describe how the parents are engaged in the transfer from the initial stages. They are shown the baby and given a chance to ask questions; they are provided with the necessary phone numbers for contacting the Children’s Hospital and furnished a map that shows them how to get there. Most important, they are encouraged to visit the hospital at any time. Once the baby has arrived at the intensive care unit, a picture is taken and shown to the mother who has remained in the other hospital.

For parents who have experienced a miscarriage or ectopic pregnancy, seeing the fetus is not generally as important an issue. Some feel that seeing the remains of the pregnancy or knowing what happened to them can only be harmful. What they do express a strong desire for is information about the cause of their loss and about the grieving process itself.

A major issue for any mother whose infant has died or is very ill is the location of her hospital room. Most mothers express their desire to be as far away as possible from healthy babies and their excited parents. The experience of hearing babies crying in the nursery or seeing them being fed by their mothers can be excruciating. Not only does the mother feel especially miserable around the constant reminders of her own emptiness and failure, but she also feels awkward and worries about making other mothers uncomfortable. She needs to face the reality of her own baby’s illness or death, but it is cruel to force her to witness other people’s joy.

Some women prefer to remain on the maternity floor, usually in a private room, either because of more liberal family visiting hours or because they do not want to feel isolated for their failure to have a healthy child. Maternity nurses who are trained to help bereaved parents may find it easier to keep the mothers on their floor, although they should have the option of visiting them elsewhere in the hospital if the mother chooses to move. Offering parents a choice of floor can be a positive way of giving them some control over what is happening to them when everything else seems out of their control.

The terrible loneliness felt by the disappointed mother becomes worse if hospital policy restricts her family’s visiting. Hospitals have reasons for rules, but strict adherence to them is not always appropriate. One grandfather mentioned his distress when he was not allowed to see his daughter and his new grandson immediately:

As soon as we heard the news I raced to the hospital. I ran in the door—I wanted to see my daughter and my first grandson before he died. But I was stopped at the entrance by a security man telling me I would have to wait two hours for the correct visiting time. I pleaded but was told this was a strict rule that he could not break. I was so frustrated that I broke down and cried. Finally he let me in.

Many hospitals do not allow a father to stay overnight in the room with the mother even though this could ease her feelings of emptiness. Having her other children visit can also be reassuring to her as well as to the children themselves. Early discharge is sometimes the best solution, and unless there are serious complications most women can leave the hospital soon after delivery.

Many bereaved parents feel out of place on the maternity floor. Because their situations are unusual, the routine nursing strategies do not apply and sometimes mistakes are made. One mother of a stillborn child complained that by error a nurse came into her room and asked cheerfully, “How is the little baby doing today?” The mother responded, “The baby is dead!” In some hospitals, an unobtrusive symbol such as a teardrop is
placed on the door of a patient who has had a loss. In that way all staff members can be alerted to try to avoid such mistakes.

Hurtful comments are one reason for parents' anger at the doctors, the nurses, and the hospital. Parents are also angry at the possibility of some medical error having caused their grief. They are angry when they receive bills for services they thought were poor or insensitive. They are angry at being given evasive answers. They are angry because they feel misunderstood and because their grief was dismissed as trivial.

The general impression of insensitivity arises from comments that some staff members make in an effort to be comforting. As one woman said:

I knew something was wrong just by the way everyone was scurrying around in the delivery room and by that terrible silence. Then we knew the baby was dead. The doctor's only comment was, "It must be congenital," as if to say it certainly must be my fault, not his. Then a nurse said, "It would be worse if you had a five-year-old that died." I suppose she was right, but it certainly didn't make me feel any better. Later, the doctor said, "You're young; you'll have lots more kids." I was appalled—I was thirty-three already. Where do they learn all these stupid comments?

Another source of anger is the way parents are approached for permission to perform an autopsy. This request occurs quickly after a death and comes as a jolt to the parents, who are not yet prepared to make such a decision.

Parents often have strong feelings or fears about an autopsy. They may be eager for such an examination to learn all they can about the baby's condition. They are especially concerned about the implications of the cause of death for future children or even others they already have. Some parents oppose an autopsy as a violation of their infant's tiny body. As one parent said, "He's been through enough. I don't want him to suffer any more probing by doctors." Others may have religious objections or worry needlessly that the body cannot be properly displayed at the funeral.

If parents are approached cautiously and with an understanding of their feelings, the initial request for an autopsy can be the beginning of discussions about what happened to the baby. Autopsy results can form the basis for further discussion during a follow-up interview. Many times results are not reported automatically and parents have to ask for them. Even if it is unlikely that an autopsy will reveal new knowledge, parents may want to eliminate any possibility that unknown problems exist. Sometimes when no autopsy is performed, parents later regret not having information that might have been revealed. The doctor should give them a chance to think over their decision and change their minds without pressure.

It is important for the medical staff to discuss funeral and burial arrangements with parents. Presenting the available options and recommending a chaplain to assist them is very helpful. Many parents, especially after a miscarriage or stillbirth, may want the hospital to take care of the body or think that this is their only option. These parents may wonder later exactly what the hospital did with the baby and fear it is somewhere in a jar on a shelf. A staff member might mention that many wonder about this and then, if the parents wish, explain what the hospital's practice is. This can be comforting to those who are afraid to ask.

Too often parents are pressured into making a decision about the disposal of the body and become angry at the insensitive way this matter is handled. Once again, they need some time to think about such an important question and to discuss it with others so that they will not make a decision in haste and shock and be sorry about it later.

Various members of the staff—doctors, nurses, social workers, midwives, chaplains—can assist parents in beginning the process of grieving by telling them that grief is normal and to be expected and by describing the many emotions they will feel over the weeks and months to come. The practice of heavily sedating the grieving mother while she is in the hospital works against her own efforts to recover.

Some professionals try to prepare parents for the thoughtless comments they are likely to hear from people trying to be helpful and forearm them with appropriate responses. A social
worker who works with parents of dying infants explained her approach:

I try to give them ammunition for dealing with insensitive people. There are comments they'll hear and be angry about, and sometimes it helps to hear them in advance. I tell them people will try to help them, saying: “You really didn’t know that baby?” They can answer that their relationship with the baby started way back with the first thought of being pregnant, that even if he lived only a day he was part of their lives for much longer than that. Or people will say: “It is for the best!” Well, it’s never for the best, it’s a terrible situation!

Often the nurse, the social worker, or the chaplain is the one who is most in touch with parents and who can provide many crucial insights. Since these professionals often do not seem as distant or hurried as the doctor, they can act as advocates and interpreters, translating parents’ and physicians’ concerns to each other. Parents may feel more comfortable in expressing fears and questions to them.

Unfortunately, many newly bereaved parents are not sure how to pose questions. They are confused about how to act and wonder what others expect from them. The nurse or social worker, attuned to their situation, can relieve much of their anxiety by telling them that their feelings are common—that whatever they feel comfortable doing is normal—and by helping them to formulate their questions. They also can be sensitive to the parents who are afraid to ask the doctor anything, either because they do not want to hear unwelcome answers or because they do not want to anger and alienate the physician. Parents whose baby is still alive can be reassured that raising questions will not cause the doctor to neglect their infant. It may even be necessary to interpret a physician’s mood to parents, since they may take every word or facial movement as a reflection on their own situation.

Health professionals around the country have made tremendous progress in the last few years in their efforts to insure that parents benefit from the best possible emotional support. Many hospitals have established “perinatal bereavement teams” and policies to make sure that every family with a loss is referred to the team member on call. The team is usually comprised of social workers, chaplains, and nurses who are trained to understand bereavement and to help families with both immediate and longer-term needs. They are the ones who make sure that families have all of the mementoes, information, and options that can be offered them.

Unfortunately most programs do not include families who have suffered a miscarriage or ectopic pregnancy. The numbers are large and the woman usually does not stay in the hospital very long. But increasingly, perinatal bereavement teams are trying to help these families as well. One unusual hospital in Pennsylvania, Lancaster Osteopathic, bought a small section of a cemetery for burial of miscarried fetuses and gives every family a photograph of the cemetery marker and an engraved memorial certificate with the date of their loss.

Follow-up meetings and support groups are often included in these programs, giving parents the feeling that their relationship with the hospital staff has not ended with the baby’s death. Follow-up is time-consuming and often parents do not want it or are afraid to take advantage of it. Returning to a hospital or an office that evokes painful memories may be too difficult. Occasionally a parent will say it is not necessary to talk, that it’s better to try to forget rather than get upset again by talking about what happened. But those who do take advantage of this follow-up are grateful and very often reassured by the information and advice they receive. Many parents later express regret that there had been no such follow-up.

Although many obstetricians do ask mothers to come in for the standard four- or six-week physical checkup, they too rarely use this visit as a time for both parents to air their worries and concerns. Some neonatologists attempt to follow up with the parents whose infants were under their care. One described his approach to these interviews:

The most important thing initially is to listen, to ask what questions they have. If you start first with reviewing the case, then they might never mention their questions. They’ll think that since
the doctor hasn't mentioned the particular point, then it must be irrelevant, so they won't bring it up.

Once these concerns have been reviewed, this physician asks the parents how they are doing emotionally, how their family is handling the tragedy, how others in the community are responding to them.

A social worker may also be involved in a follow-up. One mentioned that she used the approach of asking each parent to describe how the other was doing. This usually succeeded in opening up areas of possible concern that a person might have been reluctant to raise on his or her own.

If a woman becomes pregnant again, she may look for a different doctor, either because of dissatisfaction or simply to make the next pregnancy as different as possible from the one that ended so badly. The next time parents may have a clearer idea of what they want from a physician and a hospital—more empathy, more experience, more progressive policies—and will shop around carefully. Some, however, are very impressed by their original doctor's helpfulness and cannot imagine going to anyone else.

During the next pregnancy, the parents look for encouragement from the physicians and office nurses and for understanding of their anxieties. One woman who did not get this understanding remembers:

My doctor told me I was foolish to worry and that I would just be hurting the baby if I were too anxious. He made me feel worse. Couldn't he understand what I had been through? If it had happened to him, I'm sure he would worry just as much!

When the physician is sensitive to the parents' concern, he or she can help alleviate the anxiety—for instance, by amplifying the fetal heartbeat more often than usual for the parents to hear, and in general by understanding the reason for their fears.

A growing number of professional conferences and in-service training sessions include discussions of the psychological care of grieving parents. Research on family reactions is also growing and has led to more awareness by the hospital staff of the problems that are bound to arise.

One benefit of these sessions is that they can give staff members the opportunity to talk with each other about their own feelings of grief when a baby dies. One doctor remarked that every baby's death is painful to him. "It's always upsetting," he said. "I've never been able to get used to it." These feelings are rarely visible to the parents. A maternity nursing supervisor observed:

People think the doctors have no feelings. But I've seen them telling parents their baby has died and then a few minutes later I find them around the corner or in the staff lounge crying. This affects all of us more than people know.

Doctors and nurses may have been taught that it is "unprofessional" to become emotionally involved with patients, but the most helpful professionals are often those who can honestly share the parents' grief. A physician described his view on the importance of this openness:

One of the things that is important is to take a minute to back off and objectively assess what steps need to be taken. Keep those things in mind, and then don't be objective. Parents need people around them to act like people, not to be cool and professional. It's all right to cry.

The staff member's grief is especially acute when he or she has had the chance to take care of a baby in the nursery. Sometimes an infant may survive for months in the hospital, and the nurses begin to bring in toys and may even think of the baby, somehow, as their own. The whole staff strongly feels the death of such a baby. For some nurses, it is particularly difficult to care for an infant after treatment has been withdrawn. When staff members provide necessary emotional support for each other, they make it easier to continue working in a very stressful setting.

Parents rarely see this side of the professionals they come into contact with. To the person who has just been through a tragic event, the doctors can appear to be powerful, arrogant, and uncaring, the hospital a depressing prison. But the concept of a
professional, as psychiatrist Robert J. Lifton points out, originated with the idea that one advocates (or "professes") on behalf of the client's total needs. When the people in medical positions do understand and respond to the needs of parents, they make it easier to cope with a very troubling experience.

As one nurse described the role of medical staff: "If we can reach parents while they are still here, and if decisions and problems are handled well from the start, then we can help parents avoid long-term problems. What we're doing is really a form of preventive medicine."

"It had been an hour since we came out of the delivery room, leaving our dead baby behind. The nurse approached us with forms to sign and the startling question, 'Who is your undertaker?' We were totally at a loss. We were young and had just moved into the area, so we were astonished at the thought that we should have an undertaker just as one would have a doctor. We were angry that the hospital staff needed to know how to dispose of our baby so quickly. But it forced us to realize that our baby was really dead and that some action needed to be taken to bury her.

'We never thought for a minute that instead of a crib we'd need a casket. Instead of reading our books on child rearing, we would be reading prayers and sympathy cards. We were young, our kids were young—who thinks about cemetery plots and undertakers?"

Almost immediately after their baby's death, parents are faced with the awful necessity of deciding something they usually know nothing about. As a young couple, they are unlikely to know an undertaker or even to have attended many funerals. They are bewildered—no whom can they turn for guidance?

The hospital staff may try to make it easier for a family—particularly after a miscarriage or stillbirth—by offering to relieve them of any planning; they offer to "take care of it" for the parents. At first this may be a relief to the parents, but later they may wonder whether they could have had a service for the baby and regret that they did not.

The funeral service is one of the rituals that traditionally