The Counseling Visit

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The counseling opportunity for the health professional is generally referred to as the "home visit." While the most valuable setting for assistance to the family is probably within the home setting, it should be recognized that other areas or settings can be utilized. Periodically, the telephone may be the only means of reaching the family. The decision as to where the counseling visit should take place rests with the family and the counselor.

The counseling visit is an option for the family and may be refused by them. It is suggested that families in a period of grief do not always make appropriate decisions. Initial contact with the family in terms of determining a time and location should carry a positive and affirmative note from the counselor.

Whenever possible, the counseling session should include both parents or the persons primarily involved in caring for the infant. This is sometimes neither possible nor practical. The tone of the visit is determined by the nurse or counselor, but most families will take the lead without too much difficulty. The initial visit should be carefully managed so that the family can discuss the infant and the events surrounding his life and death without feeling interrogated or regarded with suspicion. The most frequent observation by personnel participating in such visits is that the family is grateful for someone who will listen and who is also capable of dispelling any potential guilt feelings.

While there are many similar patterns in SIDS families in terms of reactions and questions, each family must be considered unique in their appreciation of the event that has occurred. Different lifestyles and patterns provide any number of coping mechanisms and support systems. The counselor should be prepared to accept some unique attitudes that may not be within the counselor's personal attitudes or concepts.

Since SIDS occurs primarily to young parents and families, the visit is also an opportunity for the public health professional to identify other living problems that may be intrinsically involved in the death of the child but not necessarily related to the cause of death. Marital problems, inadequate housing, financial problems, single parents, and other health and emotional problems will most likely be brought to the counselor's attention. The management and assistance of other problems should be handled in such a manner as to not potentially reinforce or provoke guilt feelings related to the child's death.

In addition to its original intent, the SIDS counseling visit can be a unique opportunity to assist families living in situations that might have otherwise been overlooked or ignored by the professional and the family.

Preparing for Visits to SIDS Families

Choice of a nurse for visiting SIDS families

1. Choose as few nurses as possible to make the visits so that each nurse will benefit from seeing a number of families, making her more effective.
2. The nurse should be empathetic, having a warm effect, and be a good listener.
3. The nurse should have an interest in the program.
4. The nurse should be emotionally mature and stable.
5. The nurse should be planning to remain in her position for at least a year.

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The preparation of a nurse

1. Orientation is essential: She must be confident about the facts of SIDS.
2. She must understand the normal grief reactions and the normal grieving process. She must read, discuss, and come to grips with her own feelings about death.
3. She must be alert to abnormal or appropriate reactions; i.e., emotional rigidity (no emotion), overintellectualization (obsessed with scientific details), and refer these people to the mental health professions.
4. She must understand the special problems of SIDS families and how to bring them out.
5. She must be familiar with sources of referral-religious advisors, family counselors, psychiatric help, social workers, and SIDS parent groups.

Contacting SIDS families

1. The nurse may be the one to convey the diagnosis to the family when it is not possible for the physician to contact them. Funeral homes can be very helpful in locating families or in getting in touch with them within those first few days. It is essential to contact them immediately.
2. For making an appointment to visit the family, it is best to contact them just after the funeral services are over (within about 3 days after the death). Suggest a date and time, rather than risk the rejection of an appointment by those who are immobilized by grief and unable to plan when the decision is left up to them. In talking to a person in deep grief, the voice is a monotone, without inflection, referred to as "a wooden voice"; the answers are short and without embellishment.

Visiting the SIDS family

1. Visit within two weeks of the death—usually at about one week from the date of death.
2. Consider making these visits in street clothes, rather than in uniform, if this is allowed. It has made the visit more relaxed and friendly.
3. Allow 45 minutes to an hour for each visit.
4. Questions to ask: the following outline of questions has been prepared for the nurse to use as a guide in visiting SIDS families. It is to be used as a guide only and in no way should it take on the tone of an interrogation. It will not be possible, nor should it be attempted, to cover all points in any one interview, but in visiting and talking to hundreds of parents, these are the points most often discussed.
5. A return visit may be indicated or perhaps several, depending upon the family. The nurse may leave her name and phone number, in any case, so that the family may get in touch with her if they feel the need.

Questions for the Nurse to Ask:

1. How did the baby seem to you the week or so before his death?

   This may bring forth a history of respiratory or other minor illness. Reassurance can be given that there is nothing that could have been detected or done to prevent the death. There may be guilt feelings if they did not take the infant to the doctor. If they did take the child to the doctor, they may be blaming him for not finding anything or for routine treatment.

2. Can you tell me what happened? (time of last feeding, when put down, when found?)

   This may bring forth feelings of guilt about propping the bottle, not having checked him often enough, finding him with covers over his head, etc. They can be reassured that babies do not normally "choke to death" on milk, no matter what their position in bed. Checking a baby frequently will not prevent a death of this type. Babies do not smother in their bedclothes even when they are completely covered.

3. Had you heard of "crib death" before?

This will give you an idea of how much information is necessary.

4. Does your husband (or wife) understand the disease? (when interviewing only one parent)

   This may bring out differences in adjustment or problems of one parent blaming another. Men and women seem to grieve differently. Women generally seem to have a need to talk about the death for some time; generally they are at home with constant reminders of the infant; the death has changed their whole pattern of life for the moment. The man is usually involved in work, and this offers him a diversion from the thoughts about the death. Generally he is less inclined to talk about the death.

5. Do your relatives and friends understand the disease?

   This will give you the picture of how much help they have from those who are close to them. Often disturbing comments are made, out of ignorance, by those who care the most about the family. If those can be ferreted out, dealt with and information passed on to the offenders, much family turmoil will be avoided. An understanding, informed family can be the greatest asset.

Questions the Family May Ask:

1. Do these deaths always occur at night?

   No. They have occurred at all hours of the day and night, though more often at night because that is when most sleeping is done.

2. Do these deaths always occur during sleep?

   Yes. Some investigators have observed an occasional infant who was awake, but in a five-year study at the University of Washington, all infants dying when awake, were found to have another disease.

3. Are all infants found on their stomachs?

   No. Infants have been found sleeping in all positions—back, side, stomach.

4. What caused the blotches on the infant's face when found face down?

   The blood pools by gravity after death, causing the discolored blotches. Sometimes when the baby is then put on his back, the blood drains out of the face; but this does not mean the baby was alive.

5. What caused the baby's face to be turned down into the mattress?

   This occurs frequently when the baby is sleeping on his stomach and may be caused by a spasm at the time of death. Often blankets are pulled up over the head or the baby may get into peculiar positions during this terminal spasm.

6. Would it have made any difference if I had gotten him up sooner?

   No. As far as we know, SIDS cannot be prevented in any way. Instead of finding your baby dead, you would have to watch him die, which is no better. We know of no evidence that resuscitation can save a SIDS baby.

7. Could he have cried and I not heard him?

   No. In interviewing hundreds of families, many slept in the same room with their infants, often with the bassinet right next to the parent's bed; and no one reported any sound at all at the time of death.

8. Does this occur more often in low-income families?

   Yes. The rate is higher in low-income families, living in crowded conditions. However, this does not eliminate SIDS from middle and high income groups.

9. What caused the blood around the baby's nose and mouth?

   This is found frequently and results

from a drainage of fluid from the lungs. Tiny pinpoint hemorrhages occur in the lungs in SIDS, and these can discolor the lung fluid that drains out after death.

10. How do you know it wasn't suffocation?

    Studies have been done which prove that babies do not suffocate in ordinary bedclothes. Deaths have occurred from suffocation due to plastic bags over heads or a thin plastic sheet adhering to an infant's face, but these are rare. The changes at autopsy in babies whose faces were uncovered in the crib are identical to those in babies whose faces were covered by bedding. The very fact that SIDS spares the newborn infant proves it is not due to weakness or inability to keep the face free of bedclothes.

11. What about having another baby? Won't I be afraid? How long should we wait?

    The chances of losing another baby to SIDS are the same as for your next door neighbor who has never lost a child to SIDS. The risk is low—3 out of 1,000. You will be anxious for the first six months, but don't over protect your new baby. You should have another baby when you feel you are ready, if your doctor feels that there are no contraindications.

Points for Discussion:

1. You will have emotional "ups and downs" for a while.

   It is common to have mood swings for quite a while. One day you feel that you are finally getting back to normal, and the next day you are "down in the dumps" again. Often the anniversary of the day, of the week of the death, the date of the month, finding an item belonging to the baby, seeing another infant, walking through the baby department, etc. will be enough to bring on depression.

2. Learn to turn off the "if only's".

   Every parent goes through a series of "if only" I had gotten him up sooner, had put him to sleep in his own bed, had gotten up to check him, had covered him at midnight, etc. These thoughts have to be turned off or they continue to upset the parent. Parents have to tell themselves over and over again until they believe it, that *there is no prediction or prevention.*

3. Insomnia and bad dreams are common.

   Sleep is difficult but essential for the well-being of the parent and the family. Sometimes a mild sedative will be prescribed by the family physician. Bad dreams involving death and the deceased are frequent and may be upsetting but seem to be a normal part of adjustment.

4. Somatic complaints are frequent. (stomach ache, "heart ache," etc.)

   These complaints are common. A mother may comment that her stomach feels like "it is tied in knots." Usually just knowing that others have those same feelings is a comfort.

5. It takes time to accept reality.

   Mothers have continued to get up at night to check the baby, have heard him crying, have continued to prepare the bath and fix the baby's food for some time after the death. This is fairly common and again this fact may be reassuring.

6. It is common not to want to be left alone.

   This is a very common feeling for mothers. They find it especially disturbing to be left alone in the same house or apartment where the baby died. Many have a friend or relative come and stay with them when the husband is at work. The classic example is of the young mother who sat out in the middle of the back yard

on a tree stump whenever she was left alone at home.

7. It may be difficult to concentrate for any length of time.

   Mothers especially complain of feeling that they were "going crazy" because they could not concentrate or do routine tasks that they had done all of their lives. Reading is difficult because the mind seems to wander.

8. Anorexia is common.

   There is no appetite. Parents merely eat because they know they must. As mentioned above, the stomach may feel like it is "tied in knots." Try eating small amounts of easily digested food frequently, rather than three large meals.

9. Parents may be irritated by children and yet overly concerned for their welfare at the same time. Well-meaning friends and relatives may irritate.

   Parents, rather than outwardly clinging to the remaining children, may be irritated by their behavior. Their "tolerance level" of naughty behavior may be very low. At the same time, they may feel overly concerned for their safety and may want to escape the weight of responsibility for them. Being irritated by friends and relatives, often leaves the parent feeling guilty again for resenting those who are trying to help.

10. Children may need help in adjusting to the infant's death.

    Children are very aware of the emotional tone of the family and will be affected in some way by such a death. The very small child (toddler) is too young for an explanation and merely needs lots of love and affection for his own security. He may have some frightening thoughts that he cannot express: "The baby died in his sleep, maybe I will too. I wished they would take the new baby back, and now he's gone." He may cling to his parents and do naughty things to get their attention. The older child may have his own guilt feelings and should be encouraged to talk about the death and the infant whenever he wants to. Parents should be alert for any problem which might relate to the death: difficulty at school, reverting to bedwetting, nightmares, and other manifestations.