

Section Three — Contents

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Interviewing the family

You may be nervous before the first visit, but it is important to keep in mind that SIDS parents actively supported the legislation to fund PHN visits. SIDS parents have been helped by PHNs in the past, and will continue to be helped by them in the future.

► **Important Considerations**

- Encourage the expressions of feelings by active listening. Listen for clues indicating guilt or self-blame.
- Avoid guilt reinforcing questions: such as, “Did you feed the baby regularly?”
- Emphasize it is not your fault.
- Remember that people in grief do not always hear or remember what has been said. Be prepared to repeat.
- Discuss common symptoms of grieving for anticipatory guidance. Be aware of possible physical manifestations of grief.
- Where appropriate, validate feelings and reassure. This is a normal part of the grief process—you are not going crazy.
- Listen to each family member and give feedback when indicated. Encourage family members to listen to each other.
- Assess where each family member is in the grief process including young children. Each member of the family will pass through the grief process in their own way. Encourage family members to be patient and understanding of one another.
- Note the mood of the family and how they support or do not support each other. Be aware of the possibility of family conflict caused by the extra stress.
- Identify and emphasize family strengths.
- Before you leave give the parents your business card (attach it to the *SIDS Informational Portfolio* or a pamphlet) and invite them to call you if they have questions. Ask if they would mind if you called in a few weeks to see how they are doing or set up another meeting time for your next visit. Thank them for their time.

The Tasks of Grieving

In Dr. J. W. Worden's theory of bereavement, grief is not viewed as a series of phases through which a person passes and has little or no control over, but rather as a series of tasks, which a person must work hard to complete.

► **Task 1**

Accepting the reality of the loss

The first task is accepting the fact that the baby has died, that nothing could have prevented the death, and that the baby will never come back.

Initially SIDS families often:

- Express feelings of disbelief, and of wanting the baby back at all costs.
- Search for a cause (or blame) for the death.

► **Task 2**

Experiencing the pain of grief

The initial pain often is not as intense as the pain which comes later, when the family has begun to accept their loss and is trying to resume "normal living."

Often when the pain is the most intense SIDS families:

- Receive less comfort, as helpers move on.
- May feel isolated and/or suppress pain because of unrealistic expectations of where they should be in the bereavement process.

► **Task 3**

Adjusting to a life without the baby

As the pain of grief is released and begins to subside, family members once again begin making decisions and weighing the options that their future may hold.

SIDS families may:

- Have difficulty with the feelings of detachment from the baby which are beginning to develop.
- May struggle with issues before making decisions.

► **Task 4**

Moving On

As they make and implement decisions, family members once again begin to enjoy the people and activities that brought them pleasure before the baby died.

SIDS families will experience:

- Periods of contentment interspersed with periods of guilt and/or regret.
- Concern that they are forgetting their baby.

An indication of the completion of the tasks of grief is the realization that:

“There are other people in the world who want and need my love—and loving them does not mean I love my baby any less.”

Grief, Loss and Cultural Sensitivity

As a public health nurse, you are in a very powerful position to model and encourage a salutary response to loss. You can teach healthy grieving practices by your own actions – expressing sadness about the death, offering condolences, encouraging parents to talk to each other and advocating to see that parental needs are met. These elementary practices generally cut across many cultural variations in grieving customs.

► **Diversity is the Norm**

Today, diversity is the norm. Regardless of the population that you serve, remain open-minded and sensitive to different reactions and practices surrounding death.

- Not all cultures or people respond to grief in the same manner. Even if a parent looks like you, acts like you or talks like you, do not assume that they feel or think like you.
- Ask parents about their religious and spiritual beliefs. Ask about their rituals for honoring the dead. This validates their beliefs and customs. Learn from other cultural groups.
- Look beyond the language barrier and relate to the person. It is best that health care professionals speak the same language as their clients. However, when using a translator, keep your words to the most common usage and to a minimum. This reduces the chances of filtering or confusion. Be aware of the importance of nonverbal communication. Touch is more appreciated in some cultures than others.
- Avoid using family members as translators. It is especially important not to use children.
- Surviving children may experience sadness, confusion, and anger and may blame themselves for the death. Parents and family members need to support them during this crisis.
- Encourage the supportive presence of other family members in the home. However, do not assume that the presence of other family members in the home indicates a supportive environment.
- Refer parents to their source of faith or spiritual support.
- Remember that your best asset is your sincerity.

► **Respond to Grief with Care and Comfort**

Cultural heritage strongly shapes expressions of grief and loss. But, regardless of one's cultural background, the death of an infant can create an overwhelming crisis for parents. Grandparents, siblings, other family members and friends may also mourn the loss. Although family members might not remember exactly what is said at the time of death, they will certainly recall whether or not the health care professional displayed a caring attitude and offered comfort. Care and comfort can be shown by taking the time to sit with the family, expressing condolences, explaining what is known about the cause of death and responding to parental needs associated with the death. Parents will take solace in this kindness and remember that support for a lifetime.

Adopted from "When an Infant Dies: Cross-Cultural Expressions of Grief and Loss" by Jodi Shaefer, RN, Ph.D.; and the National Fetal and Infant Review (FIMR) Program; and "FIMR Guidelines" provided by Dawn Dailey, PHN, MSN.

Concerns of SIDS Families

The following are examples of statements made by SIDS family members. They will provide you with an idea of what to expect when speaking with family members.

Practical Concerns

- What should I do with clothes, crib, carriage, toys?
- What should I do with the pictures?
- What kind of funeral should I have?
- I wish he'd been christened.
- What do I say when people ask how many children I have?
- How will I survive the holidays, anniversary, birthday?
- What is an autopsy/should I get the report?

Natural Grief Reactions

- I cry all the time.
- I have no energy.
- I can't sleep/eat.
- I can't make decisions/care for the house.
- I'm so overprotective of the other children.
- I can't go out/I can't stay in.
- Nothing is any fun.

Feelings

- Are these feelings natural?
- I think I'm going crazy/this sounds crazy, but...
- Is it natural to cry all the time?
- I think about him all the time.
- I see her face/replay the death scene/funeral constantly even when I don't want to.

Loss

- I dream about him/want to dream about him.
- I still love him so much.
- No one wants to talk about him.
- He was so beautiful/alive/big/healthy.
- I want her name remembered.
- I can't remember the baby.

Envy/Reminders

- I can't bear to care for my sister's baby.
- I look for him when I'm at the mall shopping.
- I want to hold/look at/check other babies.
- I can't stand pregnant women/baby commercials/diaper service calls.
- What can I say to my pregnant friends/sister?

Guilt

- What could I have done?
- What did I miss?
- What if I had...awakened earlier?...found him in time?...nursed him?...not smoked/taken medicine/worked?
- If only I had dressed/covered him differently.
- Was I a good mother?
- People think it was my fault.
- Am I being punished?
- Why me, God?

Anger

- Why doesn't anyone listen/care?
- People are bugging me.
- I am ready to kill myself, husband/kids.
- My neighbors are insensitive.
- I did everything my doctor told me to do.
- Why didn't the doctor find anything?
- Why didn't they ask me questions?
- Why did the police/ambulance take so long?
- Why isn't more money spent on research?
- Why did the baby leave me?
- Why do I hear so much about other health issues?

Comments That Hurt

- You can always have another baby.
- Now that your pregnant you'll get over it.
- Anything that begins with "you should."
- Examples of "You shoulds"
 - ...feel better by now.
 - ...be thankful for your other children.
 - ...feel lucky he didn't suffer.
 - ...be glad he did not live longer.
 - ...snap out of it.
 - ...stop talking about him.

When Working With Interpreters

Interviewing patients that speak another language is a task that almost all who work in public health will have to confront at one time during their career; for many it can be a daily experience. Helping a patient who is coping with an issue as sensitive as SIDS is difficult enough when you both speak the same language, but when communication is limited by a language barrier it can be impossible. Interpreters can bridge the gap if they are carefully chosen and trained. The following is a guideline for choosing, training and working with interpreters.

► **Choosing an interpreter**

Not everyone who speaks a language can interpret for you. Translating from one language to another is not as easy as it appears. Many words and phrases have no counterpart in the other language and may require lengthy explanations to explain the concept they represent. Culture, educational background and experience can all play an important role in how an individual understands and responds to the words you speak and the questions you ask. For these reasons, it is very important that the interpreters you choose have a good understanding of both languages, and both cultures. SIDS is an emotionally charged experience, which adds to the complications of interviewing and communicating in the same language. It is further complicated when there is a language barrier. Choose your interpreters with that in mind. Here are some guidelines for choosing an interpreter.

- Look for native speakers who speak English well. Most counties have cultural councils. They are an excellent resource for interpreters. They can also be of great value when you have a particularly hard case to handle. If you provide services to families who do not speak English, and/or are from a different culture, it would be to your advantage to develop relationships with the council(s) and/or agencies in your county that serve those populations.
- Look for native speakers that have lived and worked in the country for an extended period of time. They will have a better understanding of this culture as well as their own.
- Interview the potential interpreter. Assess their knowledge of SIDS. Assess their ability to understand and empathize with the SIDS parent and you.

- Avoid using children as interpreters, the issues surrounding SIDS require maturity.
 - If you must use a family member for interpreting, take the time to prepare them by following the instructions outlined below in preparing the interpreter.
 - Develop a list of potential interpreters, but try to use the same one as often as possible. This will help you develop a good working relationship.
- **Prepare the interpreter for the job at hand**
- Educate the interpreter. Make sure that the interpreter understands SIDS, teach them what they do not know. Explain the purpose of the interview, what you expect from him/her. Encourage them to ask questions when they do not understand. Encourage them to tell you if a question(s) needs to be reworded in order to be understood or if it is offensive to the family.
 - Assess the interpreter's emotional response. SIDS is a sensitive issue. Assess the emotional response of the interpreter to the family and the interview. Debrief her/him when the interview is over. Ask the interpreter to help you assess the family's reactions and needs. Do not hesitate to ask the interpreter's opinion if you do not understand a reaction(s) from the family.
 - Never use an interpreter twice if they are insensitive to the family or seem to have a difficult time understanding you and/or translating your questions into the other language or vice versa.
- **When an emergency interpreter is needed**
- If you arrive at the home and find that the family does not speak English, you may have to use a member of the family. If that family member is too young for the subject and/or does not seem competent, it is better to set up another appointment when you can come with your own interpreter.

- If you feel that the family needs immediate help, do the best you can with what you have. Take care of any critical issues. Be honest with the family, tell them you have trained interpreters who you usually work with, and you would like to come back with one of them to finish the interview.
- However, if you must continue with the interview, when you feel misunderstood, ask the interpreter to repeat your question and explain what it means. Stick to the less complicated subjects, ask direct simple questions, and tell the family if you think there is some confusion about what is being said.
- Have your own interpreter call the family back a few days later to make sure the family understood, and to find out if they would like additional help.

► **During the interview**

- Speak to the family not the interpreter. Never assume that the family doesn't understand you. Many people understand English better than they speak it. Hearing and understanding is a different skill than speaking. Speak to them in a normal voice, they do not have a hearing problem. Remember, speaking loud will not help them understand.
- Do not make assumptions. Do not assume that they are uneducated because they do not speak English. Many immigrants are well educated and intelligent. Ask them what they know before you start, just as you would with an English speaking family. Adjust your educational intervention to their level of understanding.
- Observe body language. You do not have to speak a person's language to understand what their body language is saying. Watch for signs of discomfort or confusion and other emotions or reactions. Watch your own body language, they also do not have to speak your language to understand what your body is saying.
- Do not prejudge. Do not be overly concerned by so-called cultural barriers or reactions. Culture does influence how a person reacts, but that influence will greatly vary from person to person. Remember that the person you are speaking with is an individual and that not all individuals from a group have the same values, beliefs and customs. As you would with someone from your own culture, get to know the family before you decide how they are reacting or not reacting.
- Be yourself. Many immigrants have lived in this country for enough time to have an understanding of our culture. So be yourself, not what

you think they want you to be. All people respond positively to respect. Show yours by being kind, attentive, and sensitive to their needs.

- Seek help. If using an interpreter is a new experience for you, turn to your more experienced peers when you need help (or to the local cultural council, or church). Ask questions about the interpreters they have used and how they might handle any situation that has made you uncomfortable.
- Communicate with the interpreter. Let the interpreter know if you have questions or concerns about what is being said, how she/he is translating, etc. Your questions and concerns will help the interpreter understand what is expected and to learn to work with you.

► **Become actively involved**

- Learn proper greetings in the client's language. This will convey respect for the client and demonstrate your willingness to learn about their culture.
- Learn basic words and sentences of the client's language. Become familiar with special terminology used by clients. Even though you can't speak well enough to communicate directly, the more you understand, the greater the chance you will pick up on misinterpretations and misunderstandings in the interpreter-client interchange.

NOTES



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